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ABSTRACT

This book informs parents and families of children and young adults with cancer about the most common types of cancer in the young, treatments and their side effects, and common issues that arise with a cancer diagnosis. Aspects of the disease, including characteristics of leukemia and solid tumors, are described. Treatment issues discussed include hospitalization, surgery, chemotherapy, radiation therapy, treatment side effects, new treatments, and unconventional methods of cancer treatment. This section also addresses other common health issues including infections, activities, diet, immunizations, other medications, mouth care, dental care, bleeding, and transfusions. The second section offers tips for clinic visits and medical procedures, provides guidelines for when to call the doctor, and describes the following common medical procedures: angiogram, biopsy, blood studies, bone marrow aspiration, computerized tomography, magnetic resonance imaging, lumbar puncture, scans or radioisotope studies, and ultrasound studies. The final section is on coping with cancer. It covers dealing with the diagnosis (parents' initial reactions, accepting the diagnosis, telling the child, age-related concerns, and telling the siblings) and continuing life for all involved. Additional sources of information, support, and assistance are briefly described. A glossary defines medical and other terms used in the handbook. (DB)

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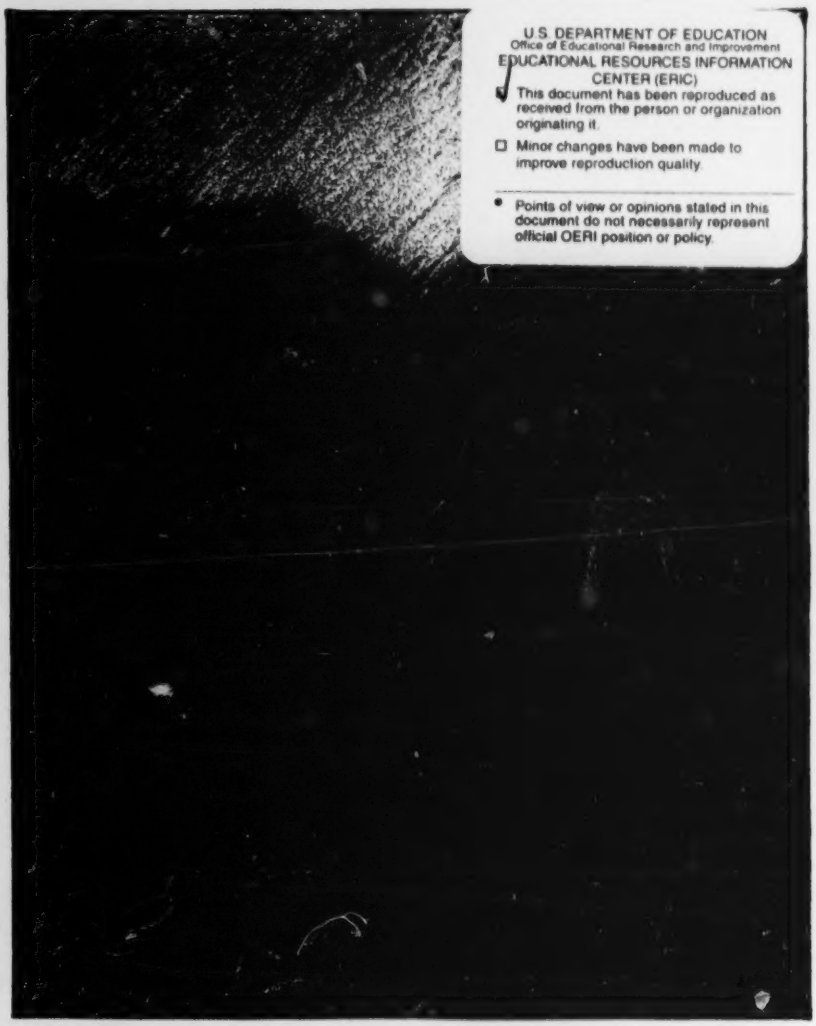
Young People With Cancer

A HANDBOOK FOR PARENTS



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Although many people have played a role in the development of this handbook, the most important contribution has come from those it is intended to serve—the parents and family members of young cancer patients, the patients themselves, and the caregivers who treat them. During the time that the National Cancer Institute's Office of Cancer Communications has made a concentrated effort in the area of coping with childhood cancer, these people have given freely of their time, experience, and expertise.

This publication has benefited from the wealth of information provided through the Candlelighters Childhood Cancer Foundation and the parents' groups in its communication system, the review and assistance of professionals who treat young people with cancer, and the insights, review, and openness of young cancer patients and their parents. Although they are too numerous to name, their contributions are gratefully acknowledged.

Foreword

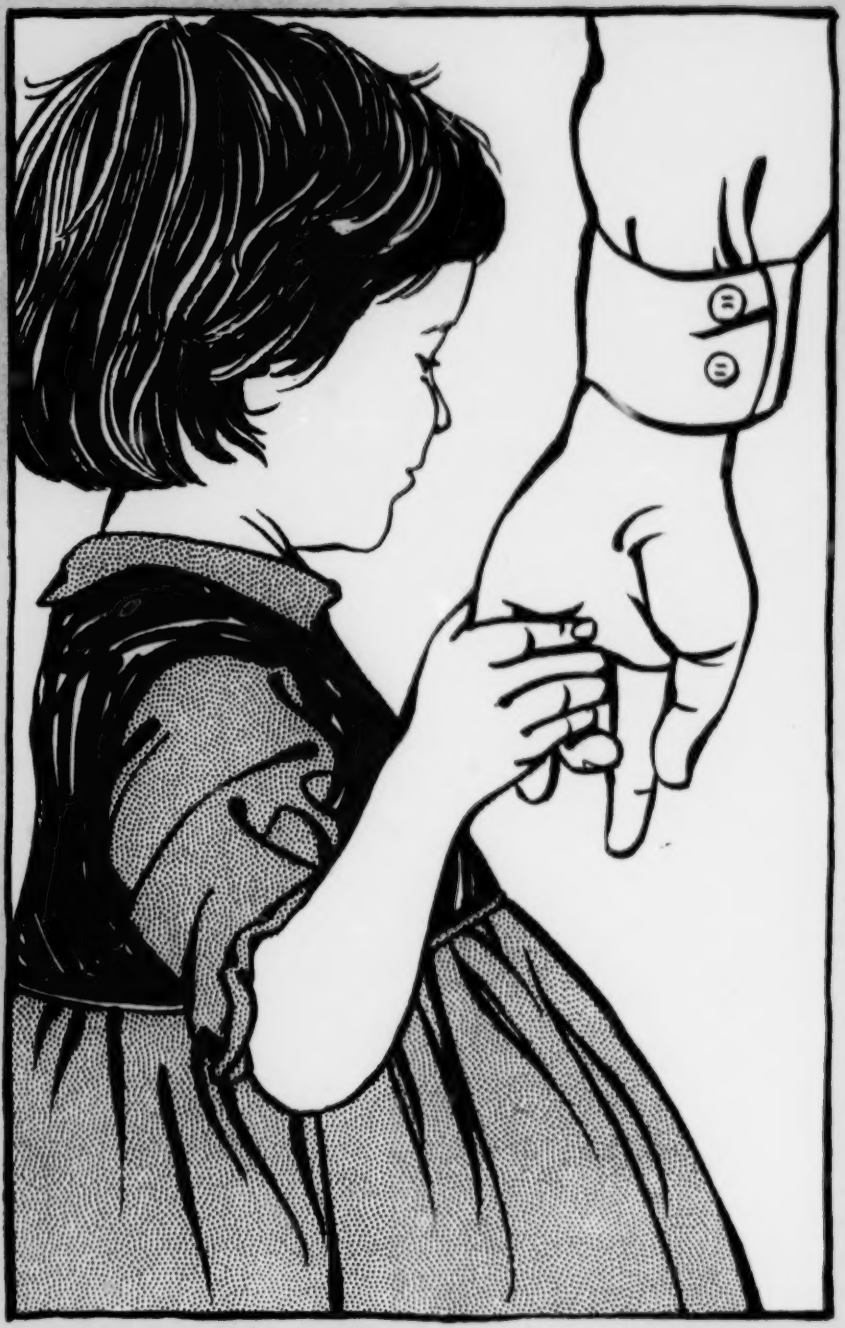
The outlook for the survival of children with cancer has improved dramatically in recent years. Childhood cancer was once considered a swift and certain killer. Today, treatment techniques capable of producing disease-free states (remissions) have increased the length of survival and, in some cases, brought about apparent cures.

Although childhood cancer in general can be viewed as a chronic, treatable illness, it is life-threatening. Treatment efforts are not always successful, and children with cancer and their families may live with uncertainty and the fear of death.

Treatment for childhood cancers is aggressive and demands much of patients and those who provide them with support and comfort. These demands are both physical and emotional and are disruptive on many levels. For the parents of young people with cancer, it is necessary to face their own fears while providing support to their sick child and to healthy brothers and sisters. They must strive to continue life in as normal a manner as possible in an abnormal situation. In their efforts, they are aided by the staff at treatment centers, by other parents, and by family members and friends, but still the primary responsibility is theirs as parents.

This book attempts to provide parents with information on the most common types of cancer, on treatments and side effects, and on the common issues that arise when a child is diagnosed with cancer. It contains medical information and practical tips gathered from the experience of others. Our aim is that this book will be of use to you and other family members in understanding the medical side of cancer and its treatment and in coping with the changes this brings to your daily life.

Samuel Broder, M.D.
Director
National Cancer Institute



Introduction

This handbook was written for you—a parent of a young person with cancer. It addresses some of the most common questions about cancer in the young, combining medical information with practical suggestions. Special consideration is given to the emotional impact of cancer on patients and family members. This handbook is designed to help you cope with the stress of a chronic disease that entails rigorous treatment, frequent visits to the doctor and hospital, interruptions in schooling and social activities, physical change, and perhaps most frightening of all, uncertainty about the future.

Because cancer in adults and children actually involves over 100 distinct diseases and no two patients or families are alike, this handbook cannot address every issue or situation that will arise. Instead, it provides a general guide to childhood cancer: what to expect from it and how to deal with it.

Direct specific questions to your family physician and/or other members of the treatment team. If you want more information in special interest areas, you may want to refer to the resources beginning on page 73.

The terms used in this handbook are those used by treatment team members when talking about your child's disease or treatment. Some of these at first may be unfamiliar to you. The glossary defines terms used in the handbook and others that might be used by your doctor or others involved in your child's care.

The Disease

Cancer is actually a group of diseases, each with its own name, its own treatment, and its own chances of control or cure. It occurs when a particular cell or group of cells begins to multiply and grow uncontrollably, crowding out the normal cells. Cancer may take the form of leukemia, which develops from the white blood cells, or solid tumors, found in any part of the body.

Despite considerable and continuing research, no one knows why children get cancer. Some common misconceptions about cancer are addressed below:

1. So far as scientists have been able to determine, nothing you or your child did or didn't do caused the disease. Cancer in children is still a largely unexplained disease, and there is no evidence that you could have prevented it.

2. Few cases of childhood cancer are due to genetic (inherited) factors.

3. In almost all cases of childhood cancer, its appearance in one child does not mean that a brother or sister is more likely to develop it.

4. Cancer is not contagious. It cannot be spread from person to person like a cold, or from an animal to a person.

5. No food or food additive has been implicated as a cause of any childhood cancer.

Leukemia

Leukemia is a cancer of the blood and develops in the bone marrow, the body tissue that produces blood cells. The bone marrow is a jelly-like substance that fills the inside of the bones.

The bone marrow makes three kinds of cells:

1. **Red blood cells** *(erythrocytes)*

They give the blood its red color. These cells pick up oxygen and carry it to the tissues. They are also known as RBCs.

2. **Platelets** *(thrombocytes)*

They help stop bleeding if there is injury.

3. **White blood cells** *(leukocytes)*

They fight infections. They are also known as WBCs. Leukemia develops in these blood cells. In leukemia, certain white blood cells escape the normal control mechanisms that direct their maturing. Instead of aging so they are able to assume certain functions, they remain young and continue to multiply. This can happen to any of three main kinds of white blood cells:

a. Neutrophils, which eat bacteria
b. Lymphocytes, which make substances to fight bacteria
c. Monocytes, which destroy foreign materials.

What Is a Blast?

In speaking about leukemia, "blast" is the short name used for lymphoblasts, the immature white blood cells. There are normal blasts and leukemic blasts. Normally, blasts compose less than 5 percent of the cells made by the bone marrow and grow to form mature white blood cells with certain typical features visible under the microscope. Leukemic blasts are abnormal because they remain immature and do not function

like mature white blood cells. In many cases, they look different from normal blasts when viewed under a microscope.

What Happens in Leukemia?

When a large number of blasts (leukemic cells) appear in the bone marrow, several things happen. As the leukemic blast cells accumulate in the bone marrow, they begin to crowd out the normal blood cells that develop there. Eventually, they take up so much room that red blood cells, platelets, and normal white blood cells cannot be produced. When that happens, the young person develops symptoms indicating that normal blood cells are not being manufactured in adequate numbers:

- If red blood cells are crowded out by leukemic cells, the blood will look thin, which makes the patient look pale. The young person also may be tired, because the thin blood cannot carry enough oxygen to the heart, lungs, and muscles.
- If blood platelets are crowded out in the bone marrow, the young person may have bleeding problems and unusual bruising.
- If the normal, mature kind of white cells known as neutrophils are crowded out by the blasts, there will be no cells to combat bacteria, and infections may occur.

In some cases, leukemic blasts may spill over from the bone marrow into the blood, where they can be seen by microscopic examination. This may cause a rise in the number of white cells in the blood (the white blood cell count). In other cases, only a few blasts appear in the blood, and the white cell count does not change much. When leukemic blasts are present in the blood, they may be carried to other places in the body and enter various body organs. Sometimes they grow in these organs as well as in the bone marrow.

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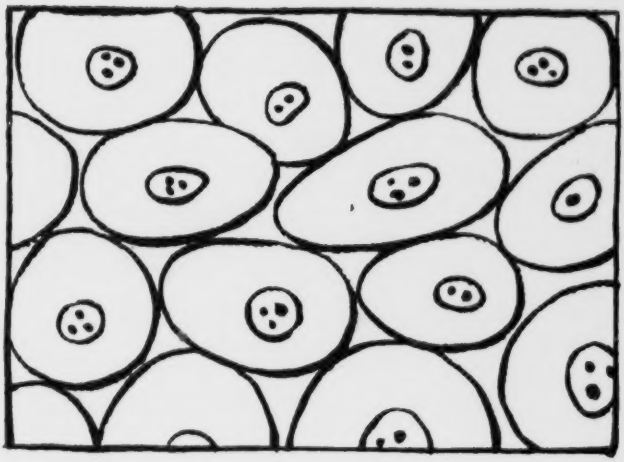


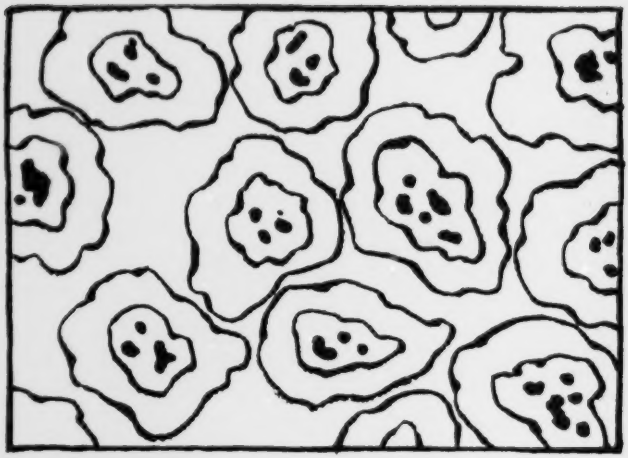
Normal cells

Kinds of Leukemia in Young People

Leukemia is not just one disease. There is actually a type of leukemia for each of the three major kinds of white blood cells—neutrophils, lymphocytes, and monocytes.

Leukemia in any one person can affect only one kind of blood cell. The most common kinds of leukemia are lymphocytic (also called lymphoblastic or lymphoid) and myelogenous (also called granulocytic, myelocytic, myeloblastic, or myeloid). Other types (monocytic, myelomonocytic, progranulocytic, or erythroleukemia) are very rare but still act much like the more common kinds.

If leukemia affects a young person quickly, it is called "acute" because it comes on suddenly and progresses rapidly without treatment. Almost all childhood leukemias are acute, but the disease is sometimes of the "chronic" type. In chronic leukemia, the bone marrow is able to produce a good number of normal cells as well as leukemic cells so that, compared to acute leukemia, the actual disease course is milder for a period of time. Even without treatment, the disease usually progresses more slowly.



Cancer cells

Acute Lymphocytic Leukemia

Acute lymphocytic leukemia (ALL for short) is commonly known as "childhood leukemia." It is the most commonly occurring cancer in children. As its name suggests, it affects the lymphocytes. Most children are between 2 and 8 years old when diagnosed, but the disease can occur in people in their twenties and thirties as well. For reasons yet to be understood, slightly more boys get ALL than girls, and it occurs more frequently among white children than black children.

Acute Myelogenous Leukemia

Acute myelogenous leukemia (AML) is also called acute granulocytic leukemia. It usually occurs in people over 25 but sometimes is found in teenagers and children. In AML, the leukemic blasts develop from the stem cells that would normally give rise to neutrophils. The characteristics of the blasts in AML are generally similar to those of acute lymphocytic leukemia, but special tests can be done to help determine whether a leukemia is myelogenous or lymphocytic.

Chronic Myelogenous Leukemia

Chronic myelogenous leukemia (CML) is not common in children. CML's distinguishing feature is the presence of very large numbers of immature neutrophil cells, which seem to mature more efficiently than blast cells. The progression of CML varies greatly, sometimes changing to a type of acute myelogenous leukemia.

Diagnosis and Treatment

Diagnosis of leukemia requires blood tests and examination of the cells in the bone marrow, because early symptoms can mimic many other diseases including mononucleosis, anemia arising from other causes, tonsillitis, rheumatic conditions, meningitis, mumps, and other kinds of cancer.

In any acute leukemia, it is necessary to determine which type of white blood cell has become leukemic, because treatment and response to it are different for each kind. Usually the type of leukemic cell involved can be determined from its appearance under the microscope, but sometimes special tests of the chromosomes and cell chemistry are needed for complete certainty. In rare instances, the cells are too young to be classified. Such cases are called acute stem cell leukemia or acute undifferentiated leukemia (AUL). Other tests such as X-rays and lumbar puncture may also be undertaken to determine if areas other than the bone marrow are involved.

The primary treatment for leukemia is combination chemotherapy, where two or more anticancer medications are used to control or eradicate the disease. Radiation, platelet and red cell transfusions, antibiotic therapy, and occasionally surgery (for unusual complications) are also a part of many treatment programs. In some forms of leukemia, bone marrow transplantation is done.

Solid Tumors

What Is a Solid Tumor?

The word tumor does not always imply cancer. Some tumors (collections of abnormally growing cells) are benign (not cancerous). In discussing tumors that are malignant (cancerous), however, the term solid tumor is used to distinguish between a localized mass of tissue and leukemia. (Leukemia is actually a type of tumor that takes on the fluid properties of the organ it affects—the blood.)

Different kinds of solid tumors are named for the type of cells of which they are composed:

Sarcomas
Cancers arising from connective or supporting tissues, such as bone or muscle.

Carcinomas
Cancers arising from the body's glandular cells and epithelial cells, which line body tissues.

Lymphomas
Cancers of the lymphoid organs, such as the lymph nodes, spleen, and thymus, which produce and store infection-fighting cells. These cells also occur in almost all tissues of the body, and lymphomas therefore may develop in a wide variety of organs.

Kinds of Solid Tumors in Young People

Lymphomas

Lymphomas are cancers of the lymphatic tissues, which make up the body's lymphatic system. This system is a circulatory network of:

- vessels carrying lymph (an almost colorless fluid that arises from many body tissues).
- lymphoid organs such as the lymph nodes, spleen, and thymus that produce and store infection-fighting cells.
- certain parts of other organs such as the tonsils, stomach, small intestine, and skin.

Lymphomas have been broadly divided into Hodgkin's disease and non-Hodgkin's lymphomas, which include a number of diseases. Hodgkin's disease tends to involve peripheral lymph nodes (those near the surface of the body), where the first sign of disease may be a painless swelling in the neck, armpit, or groin. Hodgkin's disease occurs most commonly in patients in their twenties and thirties and occasionally in adolescents; it is rare in younger children.

In children, non-Hodgkin's lymphomas most frequently occur in the bowel, particularly in the region adjacent to the appendix, and in the upper midsection of the chest, a site where Hodgkin's disease may also occur. An initial sign of disease in non-Hodgkin's lymphoma may be abdominal pain or swelling, breathing difficulties and sometimes difficulty in swallowing, or swelling of the face and neck. Non-Hodgkin's lymphomas may also occur in other organs, including the liver, spleen, bone marrow, lymph nodes, central nervous system, and bones. Lymphomas can be diagnosed definitively only through a biopsy, where a piece of tumor tissue is obtained surgically and examined under a microscope. Once the diagnosis is made, many tests must be done to determine the extent of the tumor, including special X-rays, CT scans, isotope scans, and ultrasound. Blood tests are also necessary.

In the case of Hodgkin's disease, radiation therapy is highly effective for localized disease and has been the main form of treatment. However, it is believed that most lymphomas in young people are spread throughout the body, even though tumors may be detected in only one region. Because chemotherapy acts on cells throughout the body, it is the most important aspect of treatment. Surgery and radiation therapy are sometimes valuable in particular circumstances. Except in Hodgkin's disease, treatment is usually given to prevent the spread of disease to the brain and spinal column.

Brain Tumors

Brain tumors are classified and named for the type of tissue in which they develop. As a group, brain tumors are the second most common cancers of childhood. They may occur at any age, including early infancy and in adolescence, but are seen most often in children 5 to 10 years old.

Symptoms include seizures, morning headaches, vomiting, irritability, behavior problems, changes in eating or sleeping habits, lethargy, or clumsiness. Diagnosis is often difficult, because these symptoms can and frequently do indicate any number of other problems, either physical or emotional. If a brain tumor is suspected, diagnostic tests usually include skull X-rays, a brain scan, CT scans, and magnetic resonance imaging (MRI).

Treatment depends on the type of brain tumor involved. For the most part, surgery, radiation, or both are used. Anticancer drugs that can be given intravenously or orally and penetrate the brain and central nervous system are also used to treat brain tumors.

Neuroblastoma

Neuroblastoma arises from very young nerve cells that, for unknown reasons, develop abnormally. More than half of these tumors occur in the adrenal glands, which are located in the abdominal area near the kidneys. Neuroblastoma is found in children only, with one-fourth of those affected showing initial symptoms during the first year of life and three-fourths before age 5.

Symptoms include a mass, listlessness, persistent diarrhea, and pain in the abdomen or elsewhere. Again, these symptoms can point to other conditions. Diagnostic tests include an intravenous pyelogram (IVP), blood tests, ultrasound, and other procedures, depending on the site of the cancer. Because most children with this particular cancer secrete a substance that can be detected in the urine, urine tests may also be performed. The diagnosis may be further

established by a biopsy for examination under an electron microscope.

Surgery is performed to remove as much of the cancerous growth as possible. If some remains after surgery, radiation may be used. Chemotherapy alone or combined with radiation can also be effective in treating the remaining tumor or in preventing metastases, the spread of the disease to another site.

Wilms' Tumor

Wilms' tumor is a cancer that originates in the cells of the kidney. It occurs in children from infancy to age 15, is rare in older patients, and is very different from adult kidney cancers. It may rarely be hereditary, and about 5 percent of the cases involve both kidneys.

Parents frequently bring Wilms' tumor to the attention of the doctor after they have noticed a slight swelling or a lump in their child's abdomen. Symptoms such as blood in the urine, weakness, fever, loss of appetite, or abdominal pain may or may not be present.

Diagnosis begins with a physical examination and review of the child's medical history. An IVP is the X-ray method most often used. A special X-ray tomogram of the kidney (nephrotomography), CT scan, or other specialized diagnostic X-ray tests may also be ordered. Ultrasound pictures and other types of examination may be ordered as needed.

Wilms' tumor is one of several cancers for which treatments have been developed combining surgery, radiation therapy, and chemotherapy. The way in which these three methods will be used depends upon the child's medical history and general health and, above all, on the extent of the disease. Surgical treatment of Wilms' tumor (radical nephrectomy) involves removal of the diseased kidney and neighboring tissue and lymph nodes. Radiation therapy, for example, is not often used in children under the age of 2 when their disease is localized. When radiation therapy is used after surgery, its purpose is to guard against recurrence of the cancer where the tumor has been removed. Chemotherapy is used to treat virtually all cases of Wilms' tumor.

Retinoblastoma

Retinoblastoma is a rare cancer of the eye. It may be hereditary, and one-third of the cases involve both eyes. Retinoblastoma often can be seen by looking at the young person's eye but is usually diagnosed by an examination under general anesthesia using an ophthalmoscope, an instrument used in examining the interior of the eye. The disease tends to remain localized for long periods, but in advanced stages, it can metastasize, or spread to other parts of the body. X-rays, bone marrow examination, MRI, and a bone scan can be done to check for metastases.

If diagnosed early, it is possible to destroy the tumor with radiation therapy and preserve normal vision. If the tumor is so large that there is no hope of maintaining useful vision using radiation, the eye is removed. In cases where both eyes are involved, an attempt is made to preserve vision in both eyes through treatment with radiation. When advanced disease is found in both eyes, an attempt is made to preserve vision in *at least* one eye. Whenever there is any possibility of useful vision, all efforts are made to preserve it. Chemotherapy, radiation, or both may also be used to treat metastases.

Rhabdomyosarcoma

Rhabdomyosarcoma, also called rhabdosarcoma, is a type of soft tissue sarcoma arising from muscle cells. It occurs slightly more frequently in males and usually affects children between the ages of 2 and 6. Although it can occur in any muscle tissue, it is generally found in the head and neck area, the pelvis, or in the extremities.

Although rhabdomyosarcoma tends to grow and spread very rapidly, fortunately its symptoms are quite obvious compared to those of other forms of childhood cancer. A noticeable lump or swelling is present in almost all cases. Other symptoms depend on the location: if the growth is near the eyes, for example, a vision problem may develop. If the neck is involved,

there may be hoarseness or difficulty in swallowing. Definite diagnosis relies on biopsy. Evidence of tumor spread is sought with X-rays, tomograms, gallium scan, bone scan, liver scan, and bone marrow examination. Other procedures, such as lymphangiography, brain scan, and spinal fluid examination, may also be done, depending on the tumor's location.

Traditionally, surgery has been the primary treatment, followed by intensive chemotherapy and radiation. However, if the tumor is so large that surgery presents a major risk to the patient or would result in serious disfigurement or physical impairment, then chemotherapy, radiation, or both are used to reduce the tumor's size until it can be removed more safely. In some cases, the cancer can be treated effectively with chemotherapy and radiation alone.

Osteogenic Sarcoma

Osteogenic sarcoma, also called osteosarcoma, is the most common type of bone cancer in children. It arises in the ends of the bones. The bones most frequently involved are the large bones of the upper arm

(humerus) and the leg (femur and tibia). Osteogenic sarcoma usually occurs between the ages of 10 and 25 and is more common among males than females.

Young people with this type of cancer generally complain of pain and swelling, which they sometimes blame on an injury. Diagnosis can be difficult, because the disease is easily confused with local infection, effects of injury, glandular deficiencies, arthritis, vitamin deficiencies, and benign tumors. Although osteogenic sarcoma may be suspected by the way the bone looks on X-rays, diagnosis can be confirmed only by biopsy. Because the disease commonly spreads (metastasizes) to other parts of the body, especially the lungs, chest X-rays, lung tomograms, CT scans of the chest, and an X-ray skeletal survey or bone scan may also be done before treatment.

Surgery (amputation or limb-sparing) is the primary method of treatment, followed by a course of chemotherapy using one or more anticancer drugs. A prosthesis (artificial limb) and physical rehabilitation may be important parts of therapy.

Ewing's Sarcoma

Ewing's sarcoma differs from osteosarcoma in that it affects a different part of the bone—the bone shaft—and tends to be found in bones other than the long bones of the arm and leg, such as the ribs. Like osteogenic sarcoma, it usually occurs between the ages of 10 and 25, is seen more often in males, and frequently spreads to other bones and the lungs.

Young people with this type of cancer usually have more general signs—fever, chills, and weakness—than are present in osteogenic sarcoma. Because the symptoms can point to other conditions, definitive diagnosis depends on biopsy. A bone survey, bone scans, chest X-rays, lung tomograms, liver scans, and brain scans may be done as well to look for evidence of metastases.

Treatment involves use of a combination of intensive radiation therapy and chemotherapy.

Treatment

When a diagnosis of cancer is confirmed, it is best for your child to begin treatment at a center that has an experienced staff and the resources to apply the most effective form(s) of treatment right from the beginning. Your family physician or pediatrician can help you find such a center where specialists in childhood cancer will be in charge of your child's care.

Your child's treatment will be based on medical advances learned from treating many other young people. For some types of cancer, treatment programs may be well established. However, research for effective treatments is constantly under way, and your child may be treated under a research protocol (or regimen), which is a general treatment plan that several hospitals use for treatment of one type of cancer. The protocol is carefully designed to establish the ideal type, frequency, and duration of treatment.

Still, because children's reactions to therapy vary, the treatments may need to be modified to allow for individual differences. If a child is unable to tolerate a treatment plan or protocol, and minor adjustments do not correct this, another treatment plan may be begun or a specially designed program created. Before any therapy begins, the doctor should discuss the treatment program with you, including benefits and risks, and obtain your consent. Depending on the hospital's policy on the age at which a patient's agreement is necessary to undertake therapy, your child may also be required to approve it.

The treatment plan may look complicated at first, but each of the steps will be carefully explained, and you will soon become familiar with the routine.

At the treatment center, your child may be seen by different physicians from time to time, all of whom will follow the basic treatment plan. Your child may also be examined by resident physicians, fellows, and

medical students who are working in the center as part of the educational program in cancer medicine and pediatrics. All residents and fellows are experienced physicians who are near the end of their training period, and their work is supervised by a senior physician.

In addition to these physicians at the treatment center, your family physician or pediatrician may continue to play an active role in the care of your child. With current information on the therapy prescribed for your child, your doctor can remain a source of

advice and treatment for routine medical care and problems. Especially if distance between your home and the treatment center is a factor, your local physician may be called on to do blood tests or administer chemotherapy prescribed by the center physicians; thus, the number of visits to the center may be reduced. If that is the case, your child's initial hospitalization or outpatient treatment will usually take place at the center, and you will return there for periodic checkups.

The exact type of treatment your child will receive depends on the type of cancer. Most patients receive surgery, radiation therapy, chemotherapy, or a combination of these. These treatments aim at bringing about a remission, the decrease or disappearance of symptoms of the cancer. There are two major phases of treatment: remission induction and remission maintenance. Remission induction attempts to establish a "clinical" remission, in which detectable cancer has been eliminated. If this phase is successful, maintenance therapy aims at reaching undetectable cancer cells, which experience has shown may remain in the body. Remission induction may be accomplished through surgery, radiation, or chemotherapy. Maintenance therapy involves the use of chemotherapy and may last only a few months or go on for several years.

Hospitalization

With admission to the hospital, the child enters a new world, with new people and strange machines, procedures, and routines. The child sees other patients, observes their conditions, and strives to achieve some kind of order out of the surrounding confusion. From the beginning, it is important to encourage your child to ask any and all questions, express all concerns, and seek answers to what may not be understood in the hospital environment.

Hospitalization can be a traumatic experience for any child. Experiencing difficult medical procedures and continually meeting new people who do all sorts of things to the child build up tension. The young patient may become nervous, anxious, and unruly. For the hospitalized child, some form of outlet in play is essential.

Most hospitals have playrooms for patients. These offer children an opportunity to interact with one another in a way similar to their play with friends at home. In hospital playrooms, children may relax and become less fearful and better able to cope with their feelings about hospital equipment, medical procedures, and medical personnel. They may act out their concerns in play and thus deal with them in their own way.

Playroom personnel are often trained professionals with backgrounds in psychology, special education, childhood development, social work, nursing, or recreational therapy. As part of the treatment team, they are in a position to alert other caregivers and parents about concerns the child may be able to express only through play.

If the child is confined to bed and unable to go to the playroom, recreational therapists or child life workers may pay bedside visits. A child life worker is responsible for making the hospital and treatment experience less intimidating for the child by coordinating play therapy, schoolwork, and other activities.

Playrooms may also be equipped to provide outlets for the energies of older children and adolescents, who may enjoy taking part in crafts of playing games appropriate to their ages. Video games and tape players for use in the playroom or their own rooms are popular with teens.

Hospitalization threatens the growing sense of independence in older children. The young person is taken to the doctor, taken to the hospital, given treatment. This role is passive rather than active. The lack of independence resulting from hospitalization and

cancer treatment is particularly displeasing to the adolescent, who may frequently and loudly protest the forced dependence. It is not uncommon for adolescents to refuse treatment, break hospital rules, miss outpatient appointments, or undertake activities against the doctor's orders. Besides rebelling against the feelings of dependence, teenagers may be acting on the normal adolescent resistance to authority figures and reluctance to appear different from peers outside the hospital. Some hospitals have responded by relaxing certain rules so teenagers can dress in street clothes whenever possible and have visits from their friends. Hospitals may also fill the oncology ward's refrigerator with their patients' favorite foods. Parents can help by allowing the adolescent a share of the responsibility for his or her own care and by respecting the need for independence and privacy, hard as that may be under the circumstances. But more than anything else, your teenager needs to know that you are there if you are needed and that you can be relied on for honest, dependable answers.

Surgery

For many solid tumors, surgery is the primary and most effective treatment. For very large tumors, radiation or chemotherapy is often used before surgery to reduce the size of the tumor, make surgery safer for the patient, and lessen any physical or functional defects.

The young person facing surgery is likely to be afraid. To counter some of that fear, many hospitals prepare patients for surgery by letting them visit the operating and recovery rooms, where they can meet and talk with the people who will be present during the operation. These people explain what they will be doing and how they will look. They might, for instance, bring along a surgical mask and put it on for the younger child. This advance preparation can at least ease the shock and accompanying fear of the sterile

operating room, strange equipment, and uniformed, masked personnel.

In addition, the patients should be encouraged to discuss their feelings and fears concerning surgery. Young people commonly worry about the anesthesia, whether there will be a lot of pain, how their bodies will be changed, and whether their parents will be there when they wake up. If an internal organ has been removed, some children feel a lack of wholeness afterward. Amputations for bone cancer, primarily osteosarcoma, may produce similar feelings. Amputation also means the young person must accept and learn to use an artificial limb.

Your child will have questions about the surgery, and these must be answered as honestly as possible, because the child may feel betrayed if what you said does not match up with what actually happened. You will want to learn as much about the operation as possible. The surgeon and other members of the treatment team can help you. If you wish, they may be able to arrange for your child to see and talk with another young person who has had the same type of surgery and is doing well. If a limb must be removed, the center's staff might show the child a prosthesis. If appropriate, your child may begin to practice walking with crutches even before amputation of the leg makes crutches temporarily necessary.

Chemotherapy

Chemotherapy is treatment with anticancer drugs. These drugs can be given orally (pills or liquids) or by injection. There are several types of injections: into a muscle (intramuscular, or IM), into a vein (intravenous, or IV), into an artery (intra-arterial), or into a cavity (intracavitary). Doctors also inject anticancer drugs into the spinal fluid (intrathecal, or IT) to treat brain tumors and to prevent central nervous system disease in leukemia. Often, special devices, such as catheters and pumps, are used to help deliver the drugs.

Insertion of the IV needle may be painful and, once in the vein, the drugs may cause an uncomfortable burning sensation. If the drug leaks from the vein, it may severely burn the skin, so care must be taken to make sure the IV line is securely in place, and the nurse or doctor must act immediately if the needle comes out of the vein.

Injections are generally given by physicians or nurses, but pills may be given at home. Taking chemotherapy pills can sometimes be a problem with younger children, but the tablets can be broken into smaller pieces for swallowing or powdered and mixed with apple sauce, jam, or custard. Older children, particularly adolescents, may wish to be responsible for taking and keeping track of their oral medication(s). However, it is still important for parents to be familiar with the medications and check to be sure they are being taken correctly.

Whether you or your child is responsible, you may want to develop a system for keeping track of when medications are taken. Marking a special calendar is one way of doing this.

Chemotherapy and Its Side Effects

Once in the bloodstream, chemotherapeutic drugs are taken up by cells that divide rapidly, such as cancer cells. In the cancer cell, the drugs act by interfering with the duplication and growth of the cell, primarily by preventing it from dividing or depriving it of a substance it requires to function, and the cell is eventually destroyed. Anticancer drugs can affect not only cancer cells but also other rapidly dividing normal cells such as those in the gastrointestinal tract, bone

marrow, hair follicles, and reproductive system. Because of this, unwanted side effects of the treatment can and often do occur. Most side effects, however, are temporary.

One common side effect of chemotherapy is the reduction of the bone marrow's ability to produce the normal amount of blood cells. This may put your child at greater risk for anemia (if significantly fewer red blood cells are being produced), bleeding (if production of platelets is down), or infection (if the white cell count, particularly that of the neutrophils, is low). Doctors use colony stimulating factors (CSFs), hormone-like substances that regulate the production and function of blood cells, to promote the growth of infection-fighting white blood cells. Using CSFs lessens the risk of infection in patients with a low white blood cell count as a result of chemotherapy. In general, you or your child should be particularly alert to any signs of infection, bruising, or bleeding and notify your physician if they occur.

Many side effects from anticancer drugs are possible, and the following points are good to keep in mind:

1. Most side effects can be lessened by taking appropriate measures before, during, and after chemotherapy. (See the following section for how to control side effects.)

2. Side effects vary in severity and type from person to person and treatment to treatment. Your child will not necessarily have the same reactions as another child, but it is important for you to be aware of those problems that occur commonly so you can recognize them early.

3. Most side effects are reversible and will improve after the drug is stopped. Some, such as hair loss and bone marrow depression, may lessen or disappear even without discontinuing chemotherapy.

4. Side effects of chemotherapy may be classified as common or uncommon and as acute (immediate) or delayed (days to weeks after chemotherapy).

Common acute side effects:

- Nausea and vomiting
- Pain and burning at injection site

Less common acute side effects:

- Allergic reactions (hives; rash; swelling of eyelids, hands, and feet; shortness of breath)
- Drug extravasation (leaking of drug out of vein into skin)

Common delayed side effects:

- Hair loss
- Mouth soreness and ulcers
- Constipation (especially with the drug vincristine)
- Bone marrow depression (low blood counts)

Uncommon delayed side effects:

- Jaundice (yellow tint to skin and eyes due to liver problems)
- Hemorrhagic cystitis (bloody urine due to bladder irritation—especially with the drug cyclophosphamide)
- Mental or nervous system changes (lethargy, tiredness, lack of coordination)

Each drug has the potential of producing its own side effects. Your doctor can tell you which ones your child is most likely to experience.

5. Daunorubicin or its chemical cousin, Adriamycin, may cause heart damage if the cumulative dose over time exceeds certain levels. Your physician should keep a careful record of the cumulative dose and should warn you if your child passes the usual limits.

6. Chemotherapy may cause some long-term side effects in several body organs. The physician can tell you more about these in relation to your child's specific care and treatment.

Controlling the Side Effects From Chemotherapy

Certain side effects, although not dangerous, are bothersome, and you can try to avoid or control some of these through specific measures:

1. Constipation from vincristine: Encourage increased consumption of fluids and roughage (juices, fruits, vegetables, bran cereals) starting the day before injection and continuing for a week. If the child does not have a bowel movement for a considerably longer period of time than is usual, contact your physician. If constipation is a common problem, the regular use of a stool softener may be necessary while the child is on vincristine.

2. Nausea and vomiting, also caused by several drugs, can often be relieved and sometimes prevented by certain medications. Unfortunately, no perfect drug exists to prevent nausea and vomiting. Those that are effective are most helpful if given before chemotherapy. If these symptoms are marked, ask your physician about prescribing medication to counteract them.

3. Heartburn and stomachache from prednisone and dexamethasone: To prevent this, give ½ glass of milk or 1 or 2 tablespoons of an antacid with each dose.

4. Mild to severe mouth soreness is caused occasionally by several drugs (e.g., methotrexate, Adriamycin). Good oral hygiene is important during this period. Many people use special mouthrinses to ease the discomfort. (See the discussion of mouth care in "Common Health Issues" for more information.) No particular regimens are known to prevent mouth soreness from occurring.

5. Hair loss from vincristine, Adriamycin, methotrexate, cyclophosphamide, etc.: This will occur in varying degrees in each child, depending on which drugs and which schedule of drugs are received. There is no way to prevent hair loss, short of discontinuing medication. The hair will grow back, but regrowth may take months. The new hair may be different in color and texture. In the interim, emotional stress exists, especially in teenagers. If marked hair loss appears to be occurring, your child may want to consider wearing a wig. The wearing of a wig will *not* hamper hair regrowth. Caps or scarves may also be worn.

6. Tissue burns from vincristine, daunorubicin, or Adriamycin leaking at the site of injection: Any swelling, redness, or pain occurring during an injection or up to a few days afterward should immediately be brought to the attention of the doctor or nurse. Prompt treatment may be necessary to prevent a severe burn and ulceration of the skin.

7. Hemorrhagic cystitis (irritation and bleeding from the bladder) from cyclophosphamide: The likelihood of this occasional side effect may be reduced by seeing that the drug does not rest in the bladder for a long time. This is best done by giving the drug early in the day and seeing that urination is increased by encouraging your child to drink plenty of fluids throughout the day (thirst cannot be relied on). This will assure elimination of the drug from the bladder. The amount of liquids to be given depends on the child's size, so discuss this with your physician. This complication may occur shortly after the drug is given or show up weeks or months after the patient receives cyclophosphamide, so pink or bloody urine occurring at any time after therapy should be immediately reported to the doctor.

8. Some drugs increase sensitivity to the sun, so a complete sun-blocking lotion containing PABA (check the product's list of ingredients) should be used to prevent burning.

Finally, it is helpful to discuss with your physician any of the listed side effects and any other changes that you observe in your child.

Radiation Therapy

Radiation therapy is treatment with high-energy X-rays. High levels of radiation can kill cells or keep them from growing and dividing. Radiation therapy is used to treat cancer because cancer cells are growing and dividing more rapidly than many of the normal cells around them. In addition, most normal cells appear to recover more fully from radiation effects than cancer cells.

Radiation may be used alone, in combination with surgery or chemotherapy, or both. There is no pain or discomfort during the treatment. It is much like having an ordinary X-ray taken, except that the child needs to hold still for a few minutes longer. In some cases, young children need to be sedated in order to hold still for the radiation treatment. You will not be allowed in the room during treatment, because this would expose you to needless X-rays. Younger children may find it frightening to be left alone in the room during radiation therapy. If you accompany your child to treatment, it may be reassuring to explain that you are just outside the room. In some hospitals, closed-circuit television or viewing windows allow you to watch your child receive treatment, and in these cases, the child may feel easier knowing that you can see him or her all during the treatment. Most radiation departments are willing to give you and your child a tour of the treatment area before the first treatment. During this time, the technologist will explain the machines. A trip to the radiation therapy room ahead of time may also help quiet fears about the equipment, especially its large size.

Before therapy is started, a physician specializing in radiation therapy will talk with you and explain the details of the treatment. The physician will also use dye to mark the area to be irradiated. Once in place, this dye should not be washed off for the duration of the treatments, because it will be used as a guide for aiming the radiation. While radiation therapy is being received, soap or lotion should not be used on these lines or within the radiation field, where the skin will become tender. The area should also be kept dry.

Areas of the body not being treated are often protected from radiation by special shields made of lead.

Side Effects of Radiation Therapy and Controlling Them

Your child will not be radioactive during or after radiation therapy. Neither you nor anyone else need fear contact with the child. Among the real side effects of treatment, which vary according to the site receiving the radiation, are:

1. Skin damage. The skin in the treated area may be somewhat sensitive and therefore should be protected against exposure to sunlight and irritation. During treatment, it should not be exposed to sunlight. After treatment is completed, the skin will still be sensitive, and a sun-blocking lotion containing PABA should be used to prevent burning. If the head is affected, soft hats and scarves may be worn. Your physician may also prescribe baby powder or cornstarch, an antibiotic ointment, or steroid cream to relieve itching and pain and to speed healing. Nothing, however, should be applied to the treatment area without the recommendation of the person in charge of the treatment.

2. Sore mouth (if the head and neck are within the irradiated area). Your physician may prescribe a mouthrinse, and the hints on mouth care provided in "Common Health Issues" will also help.

3. Hair loss. Hair is frequently lost from the area receiving the radiation therapy. This loss is usually temporary, with hair growth beginning about 3 months after the completion of treatment. Initial adjustment to even temporary hair loss can be difficult, but after a time, children are able to play, work, and go to school without undue embarrassment. Some will want to wear a wig, cap, or scarf.

4. Nausea, vomiting, and headaches. A few children have these symptoms following radiation therapy to specific sites, such as the head or abdomen. These problems may last for about 4 or 5 hours and can be relieved by medicines prescribed by your doctor. In terms of diet, small, frequent meals are recommended. You may want to see that your child eats 3 to 4 hours before treatment.

5. Diarrhea after radiation to the abdomen (or pelvic area). This condition usually responds to simple measures such as nonprescription drugs or medications prescribed by your doctor. A low-residue diet avoiding fresh fruits, vegetables, and fried foods may also help. Occasionally, treatment will have to be suspended until the symptoms subside.

6. Late effects. Following irradiation to the brain and/or central nervous system, some children seem to be drowsy and need more sleep. This symptom may begin at various times, even as late as 5 to 7 weeks after therapy has been completed. It usually lasts about 5 to 10 days. Several days before the drowsiness occurs, the child may lose his appetite, have fever or headache, have nausea and vomiting, and be irritable in general. This is a temporary condition; nevertheless, *it is important to report such symptoms to your physician.* Other posttherapy symptoms your doctor will want to evaluate are dizziness, sight disturbances, increased appetite, and stiff neck. None of these may occur, but if they do, you should contact the physician.

7. Long-term effects. Research suggests that radiation therapy to the head may affect intelligence and/or coordination, depending on several factors, including the age of the child at the time of exposure. In some cases, growth may be affected. Research also points to the increased possibility of developing a second tumor in an area treated with radiation. Your child's physician or radiation therapist can tell you more about these long-term effects in relation to your child and the treatment.

New Treatments

The search for new and more effective drugs to treat cancer is a continuing one. Each year, thousands of drugs are tested in experimental animals for activity against cancer. The most promising of these are further studied to determine whether they might be safe and effective for human use and to establish the proper dosage.

Newspaper and magazine reports of such research can be unintentionally misleading. A so-called new drug "cure" may refer to an agent that is effective against animal leukemia and has not yet been tested in patients. Or it may be a drug with limited usefulness in one particular type of cancer or in cancer at one particular stage. If you have any questions, discuss such reports with your child's physician, who is in the best position to evaluate them.

Some parents are concerned that if a cure for cancer is found in one hospital, it will not be known in another. Actually, the medical world is relatively small, and in this age of rapid communications, the discovery of a successful new treatment method will become generally known almost immediately.

Unconventional Methods of Cancer Treatment

Unusual remedies and approaches to cancer treatment often achieve public notoriety. As the parent of a child with cancer, inevitably you will hear of these yourself or have them brought to your attention by others. Patients, particularly older ones, may also hear of such treatments.

These treatments may involve unusual forms of therapy or strict dietary regimens that are reported to cure cancer. As a group, these treatment techniques have not been tested in the same strict method as have treatments employed by your physician. Reports of unconventional cures seldom provide enough information to compare their effectiveness with that of more conventional therapies.

The guarantee of cure these treatments offer may seem attractive when judged against the difficult treatment course of conventional therapies and the fact that your physician cannot absolutely predict the results of that treatment. If you develop an interest in an unconventional treatment or have any questions, discuss it with your physician, who should be able to provide or direct you to relevant information. The treatment team's primary concern is that your child receive the most effective treatment possible. If some magical, easy cure for cancer existed, caregivers would be the first to make it available.

Because many people have heard of these alternative methods of cancer treatment, you, or occasionally the older patient, may find yourself in the position of defending your decision to follow conventional treatment methods. This can be a frustrating situation and place a burden on you during an already stressful time. It is important to remember that suggestions are usually well intentioned and that they come from those who are not well informed about treatment advances. The best way to deal with this may be to provide these people with more information and make it clear that you appreciate their interest but that you feel your child is already receiving the best treatment available.

Common Health Issues

A number of routine health-related matters are common to all young people with cancer. Some of these are discussed below and should provide you with general information on issues of concern to you. You may want to check with your physician or others in the treatment center to see how these general statements apply to your child's specific situation.

Infections

Because of lowered white blood cell counts from chemotherapy, infections can be particularly serious. There is the potential for the development of serious and unusual infections, and any sign of infection, such as fever, should be reported to your child's physician as soon as possible.

To determine the cause of the infection, the physician may ask that cultures be taken of any sores as well as of the blood, urine, throat, and stool. If it is a bacterial infection, antibiotics will be given to control it. These may be given either orally or intravenously. Depending on the severity of the infection and your physician's policy, your child may be hospitalized. The cultures taken earlier will usually be repeated to check the course of the infection and the effectiveness of the antibiotic treatment.

Antibiotics will not be used if the infection is caused by a virus, because antibiotics are ineffective in treating viral infections. In these cases, chemotherapy may be stopped for a time and medication given to ease the symptoms while your child's blood counts and general condition are closely monitored.

Some viral infections, such as chickenpox, can be particularly dangerous to a child receiving chemotherapy, because complications from the infection may arise. Notify your child's physician immediately if your child has been exposed because certain measures can be taken, such as decreasing drug doses or using a special gamma globulin. If your child

attends school, teachers should know to inform you at once if a schoolmate develops chickenpox.

Most children who have had chickenpox are immune for life and will not contract it, even if exposed while in relapse or on chemotherapy. However, some children on chemotherapy who have already had chickenpox may, when exposed to it again, develop shingles. This is a blistery-like skin rash that resembles chickenpox but, instead of appearing all over the body, is confined to one area. Although complications from shingles are less likely than from chickenpox, notify your physician if you suspect your child has shingles.

Regular or red measles (also known as Rubeola or hard 9-day measles) may also be more serious for a child on chemotherapy. If the child is exposed to this type of measles, your physician should be notified. Regular gamma globulin may be given in an attempt to prevent or control the infection.

There is no evidence that infections play any role in activating the cancer or causing a relapse. As stated earlier, your child will tolerate most infections as well as if he or she did not have cancer. Chemotherapy may be stopped during the period of infection, depending on the severity of the infection and the child's white cell count. Your physician will be the best judge of whether this should be done.

Your child may miss some oral medications because of a gastrointestinal infection. Contact the physician or treatment center if this occurs. Brief interruptions of medicine for such reasons do not seem to jeopardize the welfare of the child.

Activities

Cancer and its management may seem to consume an overwhelming amount of your time. For the child, however, the best antidote to this unwelcome (and at times painful) attention is to encourage your child to live as normal and active a life as possible. Check with your physician to see if any special precautions should be taken.

If your child feels well, there is no need to insist on extra rest. However, there may be days, especially after chemotherapy or radiation therapy, when your child may seem lethargic or appear to need more rest. This is a normal result of the treatment. Other days normal levels of energy will return, and you should encourage your child to get regular rest and pursue normal activities.

In complete remission, there are usually no restrictions on activity.

Diet

Good nutrition is an important part of your child's treatment. In general, your child's normal diet should be continued during cancer treatment unless your physician gives you a special one. A few diet hints are listed below:

1. Build meals around your child's favorite foods. Variety is not as important as intake.

2. Small, frequent meals and snacks are attractive to most children. You can freeze portions of a favorite dish and serve them when desired.

3. Smaller bites and frequent sips of water, milk, or other unsweetened drinks will make chewing and swallowing easier.

4. Avoid empty calorie foods such as soft drinks, chips, and candy that can reduce your child's appetite without providing nutrients. By contrast, milkshakes, yogurt, fruit, juices, or instant breakfasts provide extra calories and protein.

5. Some types of chemotherapy may temporarily alter your child's sense of taste. Well-seasoned foods such as spaghetti, tacos, and pizza may seem especially good at times. Sometimes adding extra salt or sugar, or using less, may make foods taste better. However, because of fluid retention, patients on cortisone drugs should limit salt in their diets.

6. A decrease in appetite is common to some types of chemotherapy. (See the drug chart for examples.) But this must be countered with an *increase* in fluid intake beginning a few days before the chemotherapy and continuing for a few days after it.

7. If your child is taking oral medication at home, the time of day that medication is given may be critical. Some are best given in the morning, some at midday, some on a full stomach. Be sure to ask your doctor when and how medications should be administered.

Immunizations

Live virus vaccines (regular measles, German measles or rubella, mumps, polio) should not be given. They may be dangerous to a young person who is under medication that suppresses the normal response to these vaccines. Diphtheria, whooping cough, and tetanus immunizations (DPT or DT shots) are not "live" and are considered by some to be safe for those being treated for cancer. Ask your physician before allowing any immunizations to be given. If your child has never received the regular measles vaccine, report this to the physician.

Other Medications

A young person under treatment should not take any other medications without the physician's approval. It is important to note that some medications ordinarily used to treat common conditions should be avoided. For instance, when the child's platelet count is low, avoid aspirin and glyceryl guaiacolate (present in certain cough syrups). If your child is on prednisone or dexamethasone, avoid aspirin, because it may stimulate bleeding. If fever, pain, or aches are present, acetaminophen (aspirin-free pain reliever) may be used, but the presence of the condition (fever, pain, etc.) should be reported to the physician.

Mouth Care

It is especially important to keep the young person's teeth, mouth, and gums clean to protect from tooth decay and infection. Also, a child with a poor appetite who receives mouth care before meals may feel better about eating.

Teeth should be brushed after each meal, using a soft toothbrush. After each use, the brush should be rinsed well with cold water, shaken thoroughly, and hung to dry on the toothbrush rack. Disposable paper cups should be used for rinsing out the mouth. Dental floss may be used, if care is taken not to cut the gums.

To prevent the severe tooth decay that can result when saliva flow is reduced from radiation to the head and neck, older children should use a fluoride mouth-

rinse as often as recommended by the physician or dentist. Fluoride gels may be prescribed for home use.

Children whose treatment has not included radiation to the head and neck should also use a mouthrinse frequently during the day. One suggested mouthrinse is a mixture of salt and baking soda (¼ teaspoon of each in a cup of water).

Infants and toddlers can be given mouth care by wrapping a soft cloth around your finger and gently wiping the teeth and gums with a solution of mouthrinse.

When the young person has low blood counts, mouth care should be especially gentle. *Very soft* bristle toothbrushes should be used. If you prefer a Toothette (a spongy swab), discard it after use. Water jet devices or dental floss should *not* be used when blood counts are low and your child is prone to infection. Watch for sore areas or red and white patches. Alert the physician to any red or white patches, mouth sores, or irritated areas that develop in the mouth.

When mouth sores, bleeding areas, or irritated areas are present, only the mouthrinse described above or one prescribed by your doctor is appropriate. Moreover, they should be used at least every 2 to 3 hours. Your child should rinse the mouth out well after every meal and before bedtimes. Also, Q-tips or glycerin swabs can help remove food particles.

If mouth sores become painful, a local anesthetic ordered by your physician may help and can be applied as often as recommended. When your child has mouth sores, it may be easier to eat if you apply an anesthetic directly to sore gums or to other *small* areas in the mouth immediately before meals. If used as a rinse or applied to the back of the throat, however, give it to your child at least 1 hour before meals. Otherwise, the normal gag-reflex may be suppressed, and there could be a danger of choking.

If your child has dry lips, petroleum jelly or a lip pomade can prevent cracking.

Dental Care

Ideally, your child should have a thorough oral examination and any necessary dental work before cancer treatment begins. This is not always possible. Although dental work may have to be delayed because of the cancer and side effects of treatment, it should not be neglected.

When blood counts are normal, dental work is an important part of overall health care, but you should check with the physician before scheduling dental work. Even checkups should be avoided when the blood count is low.

Bleeding

A low platelet count may predispose your child to bleeding. In that case, special precautions should be taken to curtail "contact" activities. For the older child, it is wise to limit activities such as football, soccer, skateboarding, or rollerskating. To control episodes of sustained bleeding, remember the following:

- Apply pressure until the bleeding stops—a clean towel, handkerchief, or cloth *firmly* applied to the wound will slow or stop the bleeding.
- For nosebleeds, have the child sit up. Don't let your child lie down. Pinch the bridge of the nose over the bone for 10 minutes. The pressure must be tight on both sides to be effective.
- Notify the doctor promptly if bleeding continues.

Transfusions

If necessary, transfusions of whole blood or specific components of blood can be given to cancer patients. Blood transfusions may be given to control the anemia that may result from a low red blood cell count. The blood may be given as whole blood, which includes the plasma or liquid portion of the blood, or as "packed cells," a transfusion of blood from which the plasma has been removed.

Platelet transfusions may be given if your child has a low platelet count because of the disease or its treatment and is at increased risk for bleeding. Platelet transfusions are most commonly given if the patient is bleeding or is in a situation that will predispose to bleeding, such as preparing for surgery.

Because each individual has a characteristic blood type, tests are run to be sure the donor's blood is compatible with the recipient's. This process is called blood typing and cross-matching.

In transfusions of white blood cells, the need for compatible tissue type between donor and recipient is greater, and siblings and parents of the patient often serve as donors. White cell transfusions may be given to a patient with a low white count and a serious infection that is not responding to treatment.

Tips for Clinic Visits and Medical Procedures

Listed below are some ideas for making treatment and medical procedures easier. These are based on the experience of other parents and are offered only as suggestions.

1. Become involved in the health care of your child. Begin by informing yourself about your child's diagnosis and treatment. Your child's doctor or other members of the health care team can provide you with current information from books or pamphlets. Next, participate in decisions about your child's treatment. Remember, you and your child and the health professionals are partners in your child's health care. You may want to set up a meeting with the health care team, which may include nurses, doctors, social workers, nutritionists, and others, to discuss your concerns. Before that meeting, make a list of questions.

2. Prepare your child for medical tests. You need to become informed about a test before explaining it to your child. Ask the doctor or other health care team members for information and how best to explain the test to your child. Your child may react with anger or fear, but knowing this information in advance helps to build a child's trust in adults. Using language that takes into account the child's age and understanding, you can tell what will be done and why. You may want to use dolls and puppets or other playthings. Be honest about the amount and type of pain the treatment will bring. Above all, listen to your child's questions and encourage your child to express feelings about what was just heard.

3. Plan to stay with your child during a test or treatment. Your presence can do much to reassure and comfort your child and can make discussion afterward easier for you. Encourage your child to take part and make choices wherever possible. For example, your child may want to hold a gauze pad or watch for a signal. This helps children feel as if they have some control.

4. Keep a daily log of your child's temperature, activity level, feelings, sleep patterns, amount of drugs given, and any reaction, among other information. Also, record the treatments and clinic visits. You and an older child may want to work together on keeping this log. Be sure to bring this log with you to your clinic visits. It will be helpful to your child's doctors.

5. Bring a favorite toy or book to the clinic to comfort your child during the wait and the discomfort of treatment. Since waits are sometimes long and space is limited, reading, crafts, or quiet games can help pass the time. Teenagers may want to bring crafts, electronic games, playing cards, books, or magazines.

6. Be discreet when talking with other parents or with patients in the waiting room. Don't discuss aspects of your child's illness that you haven't discussed with your child.

When To Call the Doctor

Ask when your child's physician should be called. Call when you have questions or if you are unsure whether something should be reported.

In general, you should let a physician or other team member know if your child has any of the following:

1. A fever or other sign of infection of just doesn't "look well."

2. Exposure to a contagious infection, especially chickenpox or measles, unless your child is known to

be immune from prior exposure or develops a contagious infection.

3. Persistent headaches, pain, or discomfort anywhere in the body.

4. Difficulty in walking or bending.

5. Pain during urination or bowel movements.

6. Reddened or swollen areas.

7. Vomiting, unless you have been told that your child might vomit after chemotherapy or radiation.

8. Problems with eyesight, such as blurred or double vision.

9. Bleeding. In addition to obvious bleeding such as nosebleeds, signs of bleeding can be seen in the stools (red or black), in the urine (pink, red, or brown), in vomit (red or brown, like coffee grounds), or the presence of multiple bruises.

10. Other troublesome side effects of treatment, such as mouth sores, constipation (beyond 2 days), diarrhea, and easy bruising.

11. Marked depression or a sudden change in behavior.

You should also check with your child's physician when your child is due to receive any kind of vaccination or any form of dental care.

Common Medical Procedures

Evaluation and treatment of a young person with cancer involve a variety of diagnostic procedures. Many of these are repeated at intervals over the course of treatment to monitor progress and response to therapy. These procedures should be carefully explained to you and your child before they are carried out. If you have any questions, do not hesitate to ask your physician or another member of the treatment team.

Angiograms

Angiograms reveal blocking, deviation, or abnormal development of blood vessels, which may indicate the presence of a growing tumor. The blood vessels are injected with dye and then X-rayed. A similar type of study, *lymphangiography*, can be used when cancer involving the lymphatic system is suspected.

Biopsy

Biopsy is a surgical procedure used to determine whether tumor tissue is benign or cancerous. For this test, a small piece of tissue is removed from the tumor and then examined under a microscope to check for the presence of cancer cells. The tissue is examined by a pathologist, a physician who is an expert at identifying the changes in body tissue caused by disease. This microscopic study of the tissue confirms or rules out a diagnosis of cancer.

Blood Studies

Blood studies evaluate the young person's blood and the components of the blood using a variety of tests. The blood studied in these tests is obtained by drawing blood from a vein with a syringe or by a "fingerstick," in which a small prick is made in a fingertip and a few drops drawn off.

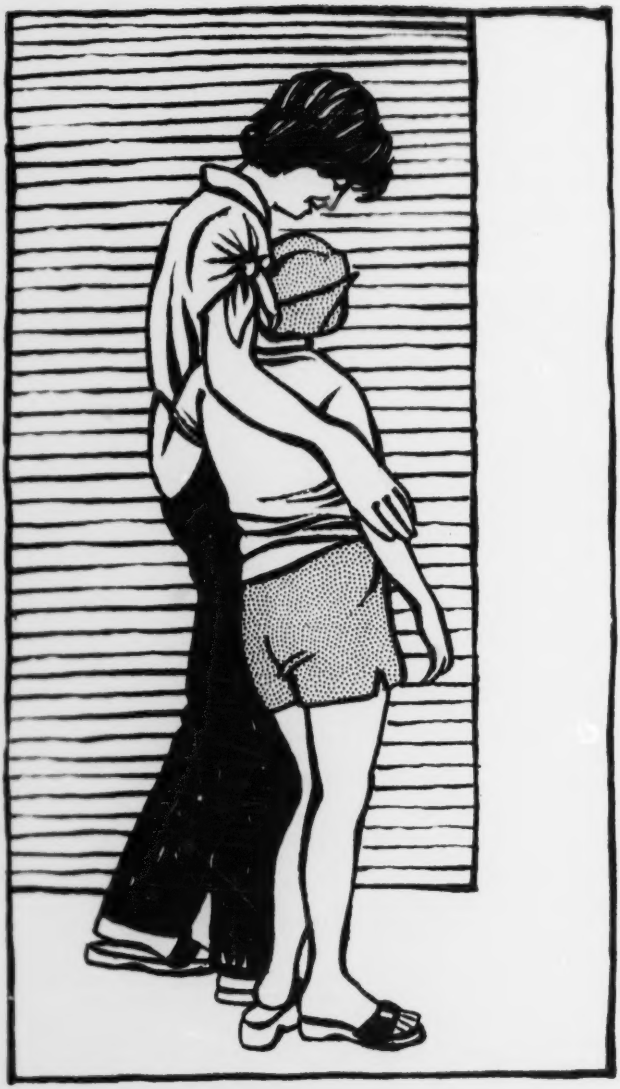
Different tests that may be performed to study the blood include:

White Blood Cell Count (WBC)

Blood cells ("blood smear") are stained on a slide and examined under a microscope. The white blood cells, those components of the blood that fight infection, are counted, and the number of those cells per cubic millimeter of blood is established. Young people receiving chemotherapy generally have a lower white cell count than normal. This test is also used to detect the presence of leukemic blasts.

Hemoglobin

Measurements are taken of the amount of hemoglobin, the substance in the red blood cell that carries oxygen and is responsible for the blood's red color. Lower amounts than normal of this substance in the red blood cells indicate anemia. If the patient shows



a low hemoglobin, physicians may do other tests to find out why and give medication (iron supplements in some cases) to correct it. A sudden appearance of anemia may suggest a relapse or be a side effect of chemotherapy.

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Hematocrit

This is a measure of the amount of red blood cells and is expressed as the percentage of the whole blood that is made up of red cells. A low count may indicate anemia.

Platelet

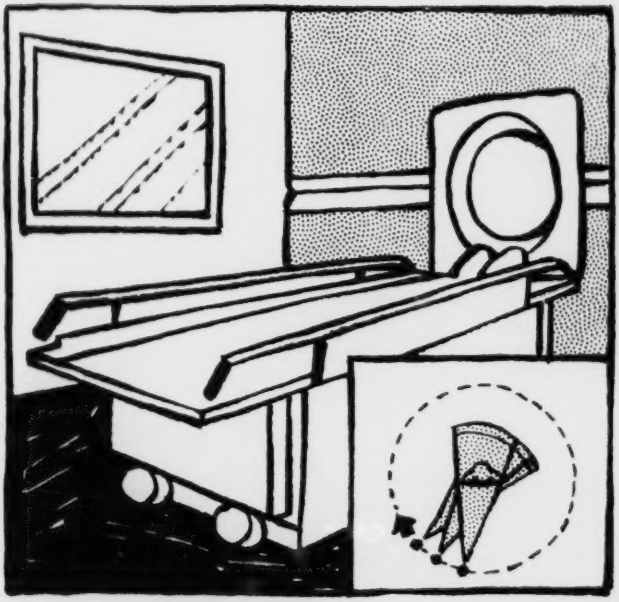
The number of platelets (the component of the blood that helps stop bleeding in case of injury) per cubic millimeter of blood is counted. A platelet count below normal range may be due to relapse, side effects of medication, or infection. If platelet counts are low, more tests may be necessary to find out the reason.

Bone Marrow Aspiration

Bone marrow aspiration evaluates the stem cells that mature into normal blood cells. The procedure is used to diagnose leukemia and to check the response to treatment. In young people with other cancers, it determines whether the disease has spread to the bone marrow.

Bone marrow aspirations in young people are usually done in the pelvis (hip bone). The patient lies on the stomach with a pillow under the pelvis, and the area is cleaned with an iodine solution to kill skin bacteria. Then the skin is numbed with a local anesthetic, and the bone marrow needle is put through the skin and into the spongy part of the bone. A sensation of pressure is felt; some patients also complain of pain. Once the needle is in place, marrow is quickly drawn into a syringe. This is the most painful phase, but lasts only a second or two.

The entire procedure usually takes about 5 minutes and is not dangerous, but it may be stressful to the patient. Attempts to reduce a patient's anxiety and get him or her to relax may reduce the pain of this procedure and certainly the stress. Usually there is only temporary tenderness at the site, and the young person can get up and go immediately afterward.



In computerized axial tomography, a computer directs X-ray beams from a rotating disc at regular intervals. The beams travel through the portion of the body being studied onto a device that registers the beam's path. The results are analyzed by a computer, and the data appear as a three-dimensional image on a TV screen.

Computerized Tomography

Computerized tomography (CT scan) is an X-ray technique for detecting masses in the body. While the young person lies still, a narrow X-ray beam directed by a computer revolves around him or her. In a matter of seconds the machine registers thousands of bits of information, which are translated into a cross-sectional picture on a viewing screen. The physician can also refer to a printout for more detailed anlaysis.

Magnetic Resonance Imaging

Magnetic resonance imaging is a new technique that uses magnetic fields and radio waves linked to a computer to create pictures of areas inside the body. The patient lies on a table that slides into a tunnel-shaped piece of equipment. Antennas within the MRI machine pick up the radio waves within and feed them into a computer which assembles a picture. Because MRI

can "see" through bone, it can provide clearer pictures of tumor located near bone, especially brain tumors. MRI takes longer than a CT scan, and it is very noisy, which may be scary for some children.

Lumbar Puncture

Lumbar puncture (L.P. or spinal tap) is used to determine whether cancer cells or infection is present in the cerebrospinal fluid (CSF) that surrounds the brain and spinal cord. It is also used to deliver anticancer drugs directly to the brain and spinal cord.

An L.P. is done while the patient is lying on one side or sitting. In either instance, it is very important that the patient be in a tight ball so the lower back is rounded and the backbone projects backward. After the young person is in position, a local anesthetic is given in the lower back. The patient is held in a tight ball and the needle is inserted between the vertebrae into the fluid space around the spinal cord. The patient may feel some pressure. A sample of CSF is collected and examined for blood and cancer cells. It also is checked for the level of sugar and protein and can be cultured to check for infection. After the fluid is collected, medicines may be given through the puncture. The patient may feel anxious, but some of this may be alleviated if the patient can learn to relax during the procedure.

Usually there are no after effects, but sometimes the young person may get a headache when sitting or standing. Sometimes the headache can be prevented by lying flat for about an hour after the procedure and by increasing fluid intake for 24 hours afterward. Fortunately, headaches are uncommon, and usually the young person can return to normal activity.

When anticancer drugs are given into the spinal fluid, nausea and vomiting may occur. Antinausea medicines may be prescribed by the physician.

Scans or Radioisotope Studies

Scans or radiosiotope studies are used to discover abnormalities in the liver, brain, bones, kidneys, and other organs. In these tests, chemicals that collect in particular organs can be "labeled" with a harmless radioactive material. The young person swallows the material or it may be injected into a vein. After a short waiting period, electronic devices are used to track the radioactive material as it collects within the body. Looking at how the material distributes itself in the body, the physician can then "see" whether an organ is functioning correctly or if it contains an abnormal mass or masses. Your child will *not* be radioactive during or after these tests.

Ultrasound Studies

Ultrasound studies determine the presence of tumors in the young person's body. Because tumors generate different "echoes" than normal tissue, sound waves above the range of human hearing can be bounced off tissue and then changed electronically into images. Ultrasound is particularly effective in diagnosis because it can "recognize" masses that are not cancerous.

Coping With Cancer

Dealing With the Diagnosis

Even though many parents suspect what the outcome of their child's diagnostic tests will be, the diagnosis confirming these fears comes as a shock. Initial explanations of the disease and treatment may be lost as parents try to come to grips with the reality that their child has cancer. This initial confusion is common, and repeated explanations of the diagnosis, treatment, and possible outcome of the disease may be necessary. Because this is a time when many important decisions must be made, as a parent, you should not be hesitant or embarrassed about asking and reasking questions about your child's disease and its treatment. Treatment centers often provide printed materials that give further explanations about cancer and its treatment that allow parents to absorb details at their own pace. Many materials are available free of charge from the National Cancer Institute (see page 76).

Parents' Initial Reactions

Parents may experience many feelings upon hearing that their child has cancer. Common reactions are denial, anger, guilt, grief, fear, and confusion. These reactions are natural and may be a way of helping you cope with the necessity of accepting a situation that you want to change but cannot. It is important to remember, however, that this is a time when your child needs your support and is particularly sensitive to your moods and feelings. Expressing these feelings too strongly may create problems for the child. A child, particularly an older child, who senses that parents do not want to acknowledge the disease, may try to protect them by not discussing his or her own feelings and fears. This feeling isolates the child from an important source of support and may only

increase concerns, because the child may imagine the situation to be far worse than it actually is.

Although the diagnosis is usually definite once the test results have been examined, parents often ask for a second opinion from another physician. Your physician or treatment center can recommend someone to you, or you may wish to get a recommendation from another source. Second opinions are useful for confirming the diagnosis and reassuring parents about its accuracy and for confirming recommended treatment or exploration of another approach to treatment. However, once the diagnosis and treatment have been agreed upon by two physicians, seeking a third opinion may in fact reflect a parent's need to find another, more acceptable diagnosis. This puts an unfair burden on the sick child and delays treatment.

Accepting the Diagnosis

Gradually parents realize that their child has cancer and nothing can change it. At this point they begin to cope with the diagnosis and their feelings about it. Some parents become angry. Targets for this anger may vary and can include God, themselves, the physician, or even the sick child for becoming ill. Because it is difficult to express anger toward the sick child, spouses and healthy children can become the scapegoats for unresolved feelings. Parents sometimes lose their tempers. Letting the anger out may occasionally be helpful. It is important to remember, however, that other members of the family experience similar feelings. Realizing that some reactions stem from this anger and talking things through with family members, treatment staff, or others who can give support may help in dealing with these feelings.

Feelings of guilt may stem from thinking that the child's illness is retribution for the parents' past mistakes. Parents may worry about how they treated the child or whether the child should or should not have received a certain vaccine. It may be difficult to accept that, despite all their efforts to understand the cause of their child's cancer, it will largely remain unexplained.

One thing parents should remember is that, as far as scientists can determine, *nothing they did or didn't do caused their child's illness.*

Parents frequently blame themselves and their physicians for delays in diagnosis. All parents want to know when the cancer began, but there is no definite answer. The onset can be rapid or gradual. Because the early symptoms of cancer are often the same as those for common childhood illnesses, early diagnosis is sometimes very difficult—even for physicians. Furthermore, medical evidence suggests that in most cases of childhood cancer, the success of therapy depends more on the type of tumor and appropriate treatment than the time of diagnosis.

Telling Your Child

One of the most difficult decisions facing parents after diagnosis is what to tell their child. In the past, there were strong cultural tendencies to shelter children from painful realities. Today, there is general agreement that the patient should be told as much about the illness as the child's age allows him or her to understand. In fact, recent studies have shown that, even when children are not told about their disease, they learn its name and its implications within the first few months of treatment. It is virtually impossible to keep from children the knowledge that they are seriously ill, because their environment has already told them they are: they take special medicines, and their parents are likely to show extra concern about their health. At home and at school, they have opportunities to overhear discussions about their condition. In the hospital, they may see and talk to other children with the same disease.

The question, then, is not whether to talk about the diagnosis, but rather how to let your child know that concerns are shared and understood and that you are willing to talk about these things with your child. The single most important and basic approach is gentle, honest communication. Failure to answer a child's question in an honest fashion undermines the parent-

child relationship at a time when the child desperately needs to communicate with the parents.

As a parent, you are the best judge of your child's moods. But you may want to keep in mind that, just because your child does not talk about the illness and the fears related to it (including death), you cannot assume he or she does not have these fears. The child who knows the illness is more serious than the usual childhood illness is undoubtedly afraid, and secrecy tends to isolate and increase fears.

Exactly when and what to tell will depend on your child's age and maturity and your attitudes. You may prefer to tell the child yourself, with or without the physician present, or you may want the doctor to do it. Use the method that makes you feel most comfortable.

Age-Related Concerns of Children

Your physician or other members of the treatment team may be able to help you determine what and how to tell the child. Some of this will depend on the child's age. In general, toddlers need only be told that they are sick, that they have to take medicine to get better, and that needles hurt, but only for a minute. Separation, abandonment, and loneliness are especially frightening to children under 5. They need to be reassured that, even if you have to leave for a while, you will be back. Children between the ages of 6 and 10 and perhaps as young as 5 have fears relating to physical injury and bodily harm. They understand that theirs is no ordinary illness; it is very serious and very threatening. Thus, they need to know that they have cancer, a serious but treatable disease. They may also be told that the cause of cancer is unknown, that they will require a lot of medicine, and that it may take some time before they really feel well again. Much can be said with honesty and hope.

Older children and adolescents are old enough to understand their diagnosis and treatment and also its implications. They may equate cancer with dying, and they need to know not only about their diagnosis and treatment, but also that cancer can often be

successfully treated and about treatment advances and increased survival rates. To these young people, the impact that cancer and its treatment will have on their normal activities, appearance, and relationships with peers may be especially important.

Reassuring Your Child

Whatever you tell your child about the illness, he or she may bring up the issue of death and the fears it creates. Be prepared to cope with questions about death, even if they are painful. Refusing to discuss death may deny your child an outlet for some strong and possibly frightening feelings, and it will deny you the opportunity to offer comfort or reassurance. In addition to discussing the child's feelings and fears, it is important to stress to all young people with cancer the fact that cancer can be treated, that research for better methods is ongoing, and that treatments are improving all the time.

Finally, young people of all ages tend to feel guilt and anger at the time of a severe illness. Guilt feelings may stem from the often subconscious feeling that disease is a punishment for being bad. Your child, therefore, needs *frequent* reassurances that he or she has done nothing wrong and is loved. The child may direct anger inward or at you for letting the illness happen. It is important for you to remember that even when your child is angry with you, your child loves you.

Many parents fear they will say something wrong that will upset their child or cause undue distress. In honest discussions this rarely happens. Even if initially upset or angry, the child will eventually benefit from the sharing of concerns with loved ones.

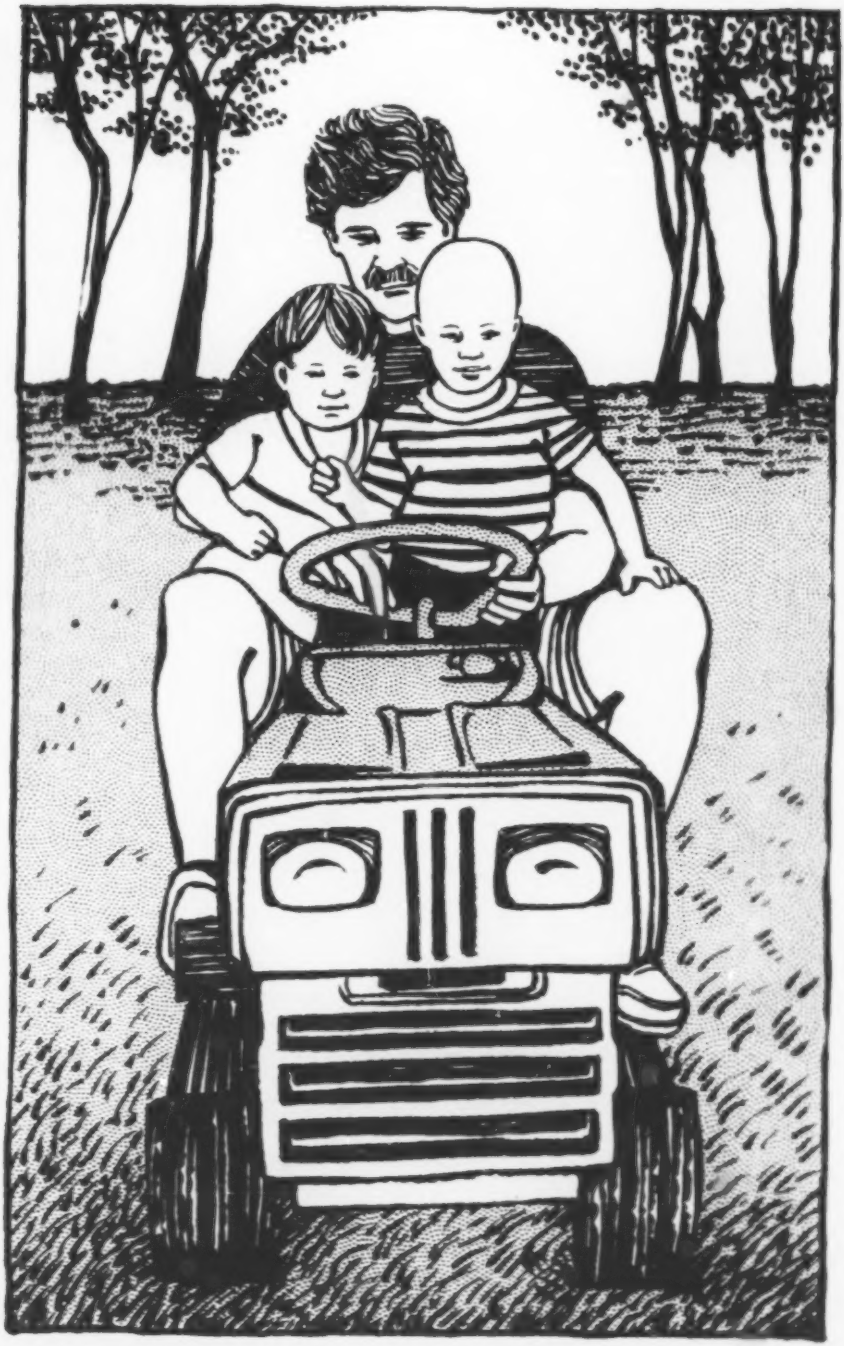
By handling the situation as openly as possible, the parent and child are free to resume as normal a life as possible. Shared awareness among the young person, parents, and medical personnel frequently has a soothing effect. The child seems happier knowing about the disease than fearing the unknown. Medical care is more successful because the child can actively partic-

ipate. Parents do not carry the extra burden of concealing the truth. Despite the uncertainties and the heartaches, everyone becomes more comfortable with the disease and with the future.

In addition to talking with their parents and caregivers, young people with cancer may want to read about cancer and hospitalization. Such materials may be obtained from the organizations listed on pages 73-77.

Telling the Brothers and Sisters

The diagnosis of cancer affects the entire family. For the siblings, the initial period can be a time of confusion and fear. Children, even young ones, are sensitive to what is happening. They are aware of a brother's or sister's hospitalization and of trips to the doctor and clinic. They notice their parents crying and trying to comfort one another. They may overhear parts of conversations that are difficult to understand. Children often conspire to figure out what is going on. Pieces of information are gathered, pooled, and analyzed. Because of this, it is important to take time early in the diagnosis and treatment process to have an honest discussion of the situation with the siblings. Encourage them to ask questions and answer these as honestly as possible. Explain the facts about cancer, keeping in mind the age and maturity of each child, and update the information periodically as the siblings and patient get older and are able to understand more. If the siblings are very young, it may be enough to say that their brother or sister is sick, will have to stay in the hospital for a while, and will need to take medicine for a long time. Older children will require more detailed information about cancer and its implications. Siblings should be prepared for physical changes in the patient, such as hair loss or amputation. If you wish, the doctors or nurses who care for the patient may be called upon to explain the diagnosis, prognosis, and treatment to the siblings or to discuss it with the entire family.



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All of the children need to know that cancer is not contagious and that they will not become sick from contact with the patient. They need to be reassured that they are healthy themselves and that the possibility of cancer running in the family is highly unlikely.

Siblings also need to be told emphatically that they are in no way responsible for the illness. Angry outbursts, such as "Drop dead!" or "I hate you," which are said by all normal children at one time or another, frequently haunt a child after learning about a sibling's illness. Feelings of guilt or wrongdoing need to be dealt with immediately. Failure to do so may result in problems later on.

Continuing Life

One of the challenges facing the family of a child with cancer is maintaining a normal life. This is not always an easy task, particularly during moments of high stress such as at the time of diagnosis and during the hospitalizations and relapses. Even when treatment is going successfully, the lives of the patient and family members are influenced by the disease and its treatment and side effects. Schedules are rearranged to accommodate hospitalization or clinic visits, family members may be separated, siblings may feel neglected. Everyone may be worried or tense.

Despite all this, the continued development of family members demands that life continue as normally as possible under the circumstances. To see that this happens, the sick child should be treated as normally as possible, the needs and feelings of the patient's siblings attended to, and prediagnosis sources of support kept open for both the parents and the child. In addition, new sources of support, such as other parents of children with cancer and treatment team members, can help parents cope.

The Parents

To cope with the child's illness and the changes this brings in your own life, you may want to consider the following suggestions:

1. Make a special effort to find private times to communicate with your spouse, or if you are a single parent, with others close to you. Don't allow all your discussions to revolve around the sick child. Make time to do things you enjoyed doing together before your child became sick.

2. Find ways to reduce the frustration you may feel when clinic visits require waiting for procedures, test results, or consultations with physicians. When your child is hospitalized, try to make it as easy on yourself as possible. Bring something to read or do while the child is sleeping or doesn't need your individual attention.

3. If work schedules permit and the distance between hospital and home is close enough, you and your spouse may alternate staying with the hospitalized child. Weekends may be a good time for a switch: the parent who has been at home or work can stay at the hospital, and the other parent can spend time at home with the other children and rest. This also allows both parents to become familiar with the child's life in the hospital and various aspects of treatment. It reduces the gap that may grow between parents when one becomes much more actively involved in the treatment than the other. If you are a single parent, other family members or friends who are close to the child may be able to stay at the hospital occasionally so you can rest.

4. Don't hesitate to turn to treatment staff for support. Most treatment centers have psychologists, social workers, nurse clinicians, or chaplains available to talk over special concerns.

5. You may want to look for other sources of support. Talk to other parents of children with cancer informally in the hospital or clinic. Your treatment center may have a parents' group supervised by a staff member for

more formal discussions. In addition, organizations outside the center may also exist. Such groups may provide support and information on how others have dealt or are dealing with situations you are facing. One national group, the Candlelighters Childhood Cancer Foundation (see "Sources of Information, Support, and Assistance" for a full description), has local chapters. Treatment center staff may be able to help you locate such a group.

When your child is in remission, it may be tempting to put all thoughts of the cancer out of your mind. And, indeed, this is a good time to get a rest from it and focus your attention on other segments of your life. However, this is also a good time to clear up any misconceptions about the cancer that the patient, siblings, or other family members and friends may have.

This is particularly true for the patient and siblings when treatment has been a lengthy process. You may need to initiate discussions to update information if you feel that this has not happened naturally during the course of treatment and that the child is concerned but reluctant to raise questions.

The Patient

Although the diagnosis of cancer will change your child's life for a time, the child still has the same needs as other young people—for friends, school, and the activities enjoyed before the illness. You can help by encouraging your child to continue a "normal" life as much as possible.

Friendships may be maintained during hospitalization or when your child is sick at home through visits, letters, or telephone calls.

School

For the school-aged child, continuing with school is vital. School is the major activity of children the same

age, and continuing to attend school will reinforce the child's sense of well-being. Furthermore, it prevents the child from falling behind others the same age in learning and in the emotional development that comes from participating in school and school activities. When your child is hospitalized, a special hospital school program may be available. If your child is receiving frequent treatments or is too ill to attend school while at home, a home tutor may be available through the school system (the treatment center may be able to help you arrange for this). But home tutoring should be undertaken with the understanding that it is directed toward easing the eventual return to school.

When the young person returns to school, the teachers, counselor, school nurse, and principal may need information about the cancer and its treatment, any absences necessary for treatment, and any restrictions on activity. Teachers should be encouraged to give normal, equal attention instead of granting special favors that the child's condition does not warrant.

Both you and your child may be anxious about the return to school. Your child may be uneasy about how classmates will react to any change in appearance, such as hair or weight loss, weight gain, or loss of a limb through amputation. You may find yourself reluctant to allow the return because you are afraid your child will become ill or you find separation difficult. Both reactions are common, but your child should return to school. Accept the child's fear of rejection and try to help deal with it. Most young people and parents find that their fears are unwarranted. Usually, classmates accept the patient and condition, and the child gains a sense of self-confidence by resuming the former role as a student. Because classmates may have questions about the child's cancer and any changes in appearance, you may want to help your child anticipate these questions and answers to them.

Discipline

Discipline is important to the normal development of all children. This is no less true when they have cancer. However, the special circumstances of these children's lives may make maintaining discipline more difficult. Having seen their child ill and in pain, parents may attempt to make up for this by giving extra presents or allowing behavior they would not tolerate in another child. They may find it difficult to discipline the child with cancer because of the uncertainty

of the future. Although it is true that for many of these young people the future is uncertain, and some will die, discipline is an important part of seeing that the quality of life is maintained.

It may also be tempting to overprotect your child, to keep the child with you and away from situations you cannot control. This may deny your child the opportunity to participate in normal activities necessary for growth and development.

Some parents say that discipline and the setting of boundaries for behavior and activity are all the more difficult because they do not know what they can reasonably expect of their child. Ask your physician or other members of the treatment staff whether therapy may be making your child behave differently and whether any limits should be set on activities. If "contact" sports should be avoided because the child's platelet count is low, you will want to see that he avoids them. But if there is no reason not to go skateboarding or participate in sports, denying this may be overprotection on your part at a time when your child should be enjoying normal activities. Some medications may cause tiredness. In these cases, the child may not have the energy to participate in some functions. Some children, however, may occasionally complain of being tired to avoid chores they do not enjoy or activities they are reluctant to try. When you know what to expect, you will be able to treat your sick child as you would any other child.

Adolescents

Many teenage patients complain that their parents are overprotective. Although this is a common cry of adolescents, it may be especially true with teenage cancer patients who are at a stage in their lives when they are naturally striving for independence but have a disease that forces them to be dependent on you and caregivers. Adolescents' attempts to achieve independence and make some of their own decisions should be encouraged within the limits set out by medical personnel.

With adolescents, special questions may arise. Those with driver's permits may want to go to the clinic alone or with a friend. Frustration over the disease-related dependence may increase their need to rebel against authority figures, which in this case could include physicians and other hospital personnel as well as you and other family members.

As with many teenagers, the questions of sexuality and drug use (including alcohol) may arise. In general, these are neither more nor less complex than when these issues are faced by adolescents who do not have cancer. In terms of drug use, however, the issue of marijuana may take on extra importance if the patient is on chemotherapy and has heard that marijuana helps prevent vomiting after chemotherapy. There is some evidence that THC, the active ingredient in marijuana, may be effective in controlling chemotherapy-induced nausea and vomiting. However, NCI scientists believe that synthetic THC can be useful only for a very few patients who have nausea and vomiting that cannot be controlled by other medications.

Siblings

Siblings of cancer patients may have many different feelings about the patient, the illness, and the attention the patient receives. While sympathizing with their brother or sister who is ill, they may still feel some resentment and believe that they are being neglected. In many cases, this is true. During times of hospitalization or when the patient is not feeling well, attention may focus on the sick child. As parents, you may not be able to pay as much attention to the siblings as you did before. You may have to miss school functions or ball games in which the siblings are participating. You may have little emotional reserve left after dealing with your sick child to talk with siblings about their concerns, to play with them, or help with their homework.

When you do have the energy, try to make special time for the siblings. Encourage them to become involved in outside activities and make a point of

recognizing their achievements. When you can, make plans to spend time alone with them and do things that interest them.

Others may focus special attention on the sick child. It is not unnatural, then, for siblings to resent the "privileged status" of the sick child in the family, neighborhood, and school and the lack of attention to their own needs. Talking with siblings about the special attention paid to the sick child, letting them know that feelings of resentment are natural, and enabling them to share in the family crisis will encourage healthy growth and maturity. Efforts should be made to give equal attention or explanations when this is not possible.

One way to help them to understand their brother's or sister's illness is by involving them in the treatment. Older children in particular welcome the opportunity to be taken into their parents' confidence and will often respond in helpful ways. Finding things for them to do for their sick brother or sister, or their worried parents, gives many young people a sense of belonging and usefulness that might otherwise be lacking in the family's focus on cancer.

Siblings may accompany you to the clinic when the patient gets treatment or, if possible, visit when the patient is hospitalized. This will allow them to see for themselves what the hospital, clinic, and treatment are like. If this is not possible because of distance, try to describe the setting and situation. Photographs may also be helpful. Siblings may need such concrete experiences or explanations to prevent the construction of fantasies about the hospital and the hospital experience. Fantasies may range from fearing that the patient is being tortured to believing that the patient is having a good time; siblings may be terrified or jealous.

Remember, the patient's brothers and sisters may be asked questions about the illness by schoolmates or others in the community. They should have enough information to answer these questions. In fact, you might want to help them anticipate questions or comments and discuss possible answers.

Behavior Changes in Siblings

Behavior changes among siblings of young people with cancer are common and can indicate that they are having trouble dealing with the situation. They may become depressed, have headaches, or begin to have problems in school. If necessary, counseling can help them cope with their feelings, and treatment center staff can help with this. If their teachers are aware that a brother or sister has cancer and that this might affect the student, teachers can alert you if problems arise at school.

Remember that siblings, like all children, don't care about tomorrow and want equal treatment and attention today. It helps to appreciate them as individuals and to make a special effort to keep in touch with their needs.

Family and Friends

A diagnosis of cancer affects not only the patient's parents and siblings but also the grandparents, other relatives, and family friends. Ideally, these people can provide support and assistance. They can babysit and spend time with the siblings, stay with the sick child to relieve you, or assist in the many practical problems that arise when a household must continue to function under stress.

Unfortunately, they are not always able to do this. Grandparents may feel particularly lost and helpless, because they are concerned about their grandchild and at the same time cannot stop the suffering of their own child. If grandparents do not understand and accept the situation, you may find yourself in the difficult position of dealing with your own emotional difficulties while attempting to support the grandparents. Treatment team members may be helpful; they can explain the child's condition to the grandparents. Being allowed to participate in meetings of parents' groups may also help grandparents deal with their feelings about the child's illness.

Each family has its own way of relating to relatives, friends, and neighbors. Above all, initial honesty is of real value in the long-term handling of any problems.

People want and need to help, but they may need assistance from you to do so. They will need information about the disease and its treatment. Some may have to be told such basics as the fact that cancer is not contagious.

In general, you and your sick child must take the lead in showing others how you want to be treated.

You may need to point out to family and friends that too much attention or indulgence does not help the patient. For yourself, you may need to show others that you want to be treated as you were before, and although your time may be limited, you would like to be included in activities you previously enjoyed together.

Your employers may also need to be told about your child's sickness so they can understand the reason for requests for time off from work. If you feel it is necessary, the child's doctor may write your employer and explain the situation.

Finally, in their efforts to help, people will give all sorts of advice. If their comments are confusing or upsetting, make a point of discussing them with medical personnel.

Finances

The cost of your child's treatment may cause additional pressure in an already tense situation. The desire to have the best in care may be offset by fear about the costs and how they will be met. As soon as financial questions arise, ask your doctor or the social worker for help.

Because health and life insurance questions can influence major health decisions, you'll need a clear understanding of the coverage your policies offer. Caregivers, particularly medical social workers, can clarify individual policies and help you fill out forms.

You should also keep complete records; store your bills and insurance forms together for easy reference at tax time. Keeping track of bills, your payments, and insurance payments by date and type of charge will simplify this further. Current records of bills and payments can be kept by listing them on a single sheet using the following format suggested in Nina Cottrell's *Coping at Home with Cancer:*

Date	Paid	Bill From	Total Charge	Ins. Paid	We Paid
7/1/90	Ch. 213	XYZ Surgery	$408.00	$365.42	$42.28

Treatment center staff may also be able to help you with other costs associated with cancer treatment. Check with them to see if you are eligible for special rates for parking or food at the hospital. If your child is hospitalized or needs daily treatment away from home, lodging costs for parents may be substantially reduced if a Ronald McDonald House (described in "Sources of Information, Support, and Assistance") is available or other special arrangements have been made. Medical social workers may be familiar with other programs, such as those of voluntary cancer-related organizations (including those listed in "Sources of Information, Support, and Assistance") or state or local programs, that may be able to assist you.

Sources of Information, Support, and Assistance

Candlelighters Childhood Cancer Foundation

Candlelighters Childhood Cancer Foundation is an international organization of parents whose children have or have had cancer. The name is taken from the saying that "It is better to light one candle than to curse the darkness."

Not all groups are called Candlelighters; the Wisconsin organization, for example, is LODAT (Living One Day At a Time).

Candlelighters was created in 1976. Headquartered in Washington, D.C., it maintains communications between parents and professionals through quarterly newsletters and between groups through bimonthly newsletters. It publishes a youth newsletter and a bibliography for parents, operates a parent information service, offers information and assistance in forming new groups, and makes available a variety of handbooks to such groups.

Family support groups under the aegis of Candlelighters have many functions, including:

- exchanging practical information and ways of dealing with common problems;
- providing an outlet for the frustrations of those under stress through self-help sessions;
- offering a social outlet for parents and siblings, reducing the sense of isolation often imposed by cancer;
- disseminating information through meetings featuring medical speakers, psychologists, or insurers; and
- directing families to professional counseling.

Some of the local chapters have such services as a toll-free hotline and a program that provides visits to the oncology areas of hospitals for the parents of newly diagnosed patients.

For more information on Candlelighters chapters and programs, contact:

Candlelighters Childhood Cancer Foundation
7910 Woodmont Avenue
Suite 460
Bethesda, MD 20814
(301) 657-8401 or 800-366-CCCF

American Cancer Society

The American Cancer Society (ACS) is a national voluntary organization offering programs of cancer research, education, and patient service and rehabilitation.

Local ACS units conduct service programs for cancer patients and their families, including:

- information, counseling, and guidance concerning ACS services, community health services, and other resources;
- equipment loans for care of the homebound patient;
- surgical dressings; and
- transportation to and from treatment.

Depending on the facilities and resources of the units, these programs may be expanded to include home health care, blood programs, social work assistance, medications, and a complete rehabilitation program.

For further information, consult local telephone directories for the closest ACS office or contact:

American Cancer Society
National Headquarters
1599 Clifton Road, N.E.
Atlanta, GA 30329
1-800-ACS-2345

Leukemia Society of America, Inc.

Financial assistance and consultation services for referrals to other means of local support are offered by chapters of the Leukemia Society of America to cancer patients with leukemia and allied disorders. Financial coverage is reserved for outpatients and pays up to $750 per patient per year of costs not covered by other sources. The program includes payment for drugs used in the care, treatment, and/or control of leukemia and allied diseases; laboratory costs associated with blood transfusion; transportation; and up to $300 of costs for X-ray therapy for early Hodgkin's disease and up to $300 of costs for cranial radiation for children with acute lymphocytic leukemia.

For more information about the program and its local chapters, contact:

Leukemia Society of America, Inc.
600 Third Avenue
New York, NY 10016
1-800-955-4572

Cancer Information Service

The NCI-supported Cancer Information Service is a toll-free telephone inquiry system that supplies information about cancer and cancer-related resources to the general public, cancer patients and their families, and health professionals. CIS offices do not diagnose cancer or recommend treatment for individual cases. They do provide support, understanding, and rapid access to the latest information on cancer and local resources. Telephone information may be supplemented by booklets and other printed materials. All calls are kept confidential, and you do not need to give your name.

For additional information and publications on cancer, write to the Office of Cancer Communications, National Cancer Institute, Bethesda, Maryland 20892, or call the toll-free telephone number of the Cancer Information Service at

1-800-4-CANCER.

Spanish-speaking staff members are also available.

PDQ Database

The National Cancer Institute has developed PDQ, a computerized database designed to give doctors quick and easy access to:

- the latest treatment information for most types of cancer;
- descriptions of clinical trials that are open for patient entry; and
- names of organizations and physicians involved in cancer care.

To get access to PDQ, a doctor can use an office computer with a telephone hookup and a PDQ access code or the services of a medical library with online searching capability. Cancer Information Service offices (1-800-4-CANCER) provide physicians with PDQ searches and can tell doctors how to get regular access to the database. Patients may ask their doctor

to use PDQ or may call 1-800-4-CANCER themselves. Information specialists at this toll-free number use a variety of sources, including PDQ, to answer questions about cancer detection, prevention, diagnosis, treatment, and rehabilitation.

Ronald McDonald Houses

The first Ronald McDonald House opened in 1974 as a place where out-of-town families can stay while their children are being treated at the Children's Hospital of Philadelphia. Since that time, other houses have opened in other major cities. In general, a Ronald McDonald House is available for families of seriously ill children and provides lodging at economical rates.

There are more than 150 Ronald McDonald Houses worldwide. A child life worker or social worker may be able to help you locate one in your area. For further information about the Ronald McDonald House program, contact:

Ronald McDonald House Coordinator
c/o McDonalds Corporation
1 Kroc Drive
Oak Brook, IL 60521
(312) 836-7100

Home Care for the Dying Child

Although treatment efforts are successful for many children with cancer, this is not always the case. When treatment is not successful and the child's disease becomes terminal, some parents may wish to have their child die at home rather than in the hospital. The patient may also prefer it. Parents who have taken their child home have shown that it is possible to provide quality care for their dying child when assisted by nurses, doctors, and other health professionals.

A home care program for children may exist in your area, but if one doesn't, you and the treatment center or a home health agency may have to work out the arrangements necessary for you to care for your child successfully. Coordination between parents and health care personnel is essential to success in caring for

dying children. A home care nurse can help parents care for their child, help acquire any necessary equipment such as hospital beds or wheelchairs, and provide emotional support for parents.

Information on home care is available from Children's Hospice International. This organization can provide referrals for home care and hospice care in your area. Informational materials also are available. Contact:

Children's Hospice International
901 North Washington Street, Suite 700
Alexandria, VA 22314
1-800-242-4453

Glossary

Acute: Occurring suddenly or over a short period of time.

Adjuvant Chemotherapy: The use of anticancer drugs after surgery in patients whose cancers are most likely to recur.

Alopecia: Hair loss.

Anemia: A condition in which blood is deficient in red blood cells, hemoglobin, or total volume of red blood cells.

Antimetabolites: Anticancer drugs that closely resemble substances needed by cells for normal growth. The tumor cell uses the drug instead and "starves" for lack of proper substance.

Benign Tumor: A noncancerous growth that does not spread to other parts of the body. Outlook for recovery is usually favorable with treatment.

Biopsy: The removal and microscopic examination of tissue from the living body for purposes of diagnosis.

Blast Cells: An immature stage in cellular development before appearance of the definitive characteristics of the cell.

Blood Typing and Cross-Matching: The blood cells contain factors that are not the same in all people. Before a transfusion can be given, blood samples from the donor and recipient are typed, or classified (type A, B, AB, or O). Once the two blood samples have been typed, they are cross-matched to be absolutely sure that they are compatible. This is done by placing red cells of the donor in a sample of the recipient's serum and red cells of the recipient in a sample of the donor's serum. If the blood does not "clump," or agglutinate, the two bloods are compatible. Techniques for typing white blood cells and platelets are similar but more complex. (See HL-A.)

Bone Marrow: The spongy material that fills the cavities of the bones and is the substance in which many of the blood elements are produced. In order to determine the condition of the marrow, a doctor may take a small sample from one of the bones in the chest, hip, spine, or leg. Such examinations are performed with the help of local anesthesia.

Bone Marrow Transplant: Procedure in which a patient's bone marrow is destroyed by chemotherapy or radiotherapy and replaced with new bone marrow from a donor, usually a sibling with HL-A (human histocompatibility antigens) identical to the patient's.

Cancer: A general term for about 100 diseases characterized by uncontrolled, abnormal growth of cells. The resulting mass, or tumor, can invade and destroy surrounding normal tissues. Cancer cells from the tumor can spread through the blood or lymph (the clear fluid that bathes body cells) to start new cancers in other parts of the body (metastases).

Carcinogen: A chemical or other agent that causes cancer.

Carcinoma: Cancer of the tissues that cover or line the body surface and internal organs.

CT Scan *(computerized tomography):* Diagnostic X-ray procedure in which a computer is used to generate a three-dimensional image.

CBC *(complete blood count):* A series of tests to examine components of the blood. The tests are useful in diagnosing certain health problems and in following the effects of treatment.

Chemotherapy: Treatment with anticancer drugs.

Child Life Worker: Professional who is responsible for making the hospital and treatment experience less intimidating for the child by coordinating play therapy, schoolwork, and other activities.

Chronic: A term that is used to describe a disease of long duration or one that is progressing slowly.

Clinical: In general, pertaining to observation and treatment of patients. Clinical research is a term applied to the study and treatment of patients.

CNS *(central nervous system):* The brain and spinal cord.

CSFs *(colony stimulating factors):* Hormone-like substances that regulate the production and function of blood cells, to promote the growth of infection-fighting white blood cells.

Combination Chemotherapy: The use of two or more anticancer medications for treatment of an individual cancer patient.

Combination Therapy: The use of two or more methods to treat an individual cancer patient, e.g., surgery and radiation therapy.

Culture: A laboratory procedure in which micro-organisms contained in samples of blood, secretions, or other body fluids are cultivated in special nutrients; used to determine the presence and type of infectious agents.

DNA *(deoxyribonucleic acid):* The basic material of life. DNA is a long, chain-like chemical found in the nucleus of all cells. The segments of the chain are the genetic code that guides the development of every cell.

Erythrocytes: Red blood cells. Their main protein component, hemoglobin, carries oxygen from the lungs to all parts of the body.

Extravasation: Leaking of the drug out of the vein and into the skin.

Gamma Globulin: A class of protein components of the blood containing antibodies effective in defending the body from certain micro-organisms.

Gastrointestinal: Pertaining to the digestive tract, which includes the mouth, throat, esophagus, stomach, small intestine, large intestine, and rectum.

Granulocytes: One type of white blood cell that destroys invading bacteria.

HL-A *(human histocompatibility antigens):* These antigens appear on white blood cells as well as cells of almost all other tissues and are analogous to red blood cell antigens (A, B, etc.). By typing for HL-A antigens, donors and recipi-

ents of white blood cells, platelets, and organs can be "matched" to ensure good performance and survival of transfused and transplanted cells.

Hematologist: A physician who specializes in the study of blood diseases.

Hematology: The study of blood and blood-forming organs.

Hemoglobin: The iron-protein component in the red blood cells that carries oxygen to the tissues.

Hemorrhage: A general term for loss of blood, often profuse, brought about by injury to the blood vessels or by a deficiency of certain necessary blood elements such as platelets.

Hyperalimentation: Intravenous administration of nutrients, bypassing the gastrointestinal tract. It is also called total parenteral nutrition (TPN).

Immune System: The body's system of defenses against disease, composed of certain white blood cells and antibodies. Antibodies are protein substances that react against bacteria and other harmful material.

Immunology: Study of the body's natural defense mechanisms against disease.

Immunotherapy: An experimental method of treating cancer that uses substances that stimulate the body's immune system.

Infection: The invasion and multiplication of disease-producing organisms in the body.

Informed Consent: The permission given by a person before surgery or other kinds of treatment. The patient, or a parent or guardian, must understand the potential risks and benefits of the treatment and legally agree to accept those risks.

Intramuscular *(IM):* The injection of a drug into muscle tissue, where it is absorbed into the bloodstream.

Intravenous *(IV):* The administration of a drug or fluid directly into a vein.

Intravenous Pyelogram *(IVP):* An X-ray examination of the kidneys that depends on accumulation and visualization in the kidney of a special substance that is injected into a vein.

Isotopic Scan: A diagnostic procedure for examining the brain, bones, and other organs. In this procedure, a radioactive substance is introduced intravenously, collects in certain organs, and is then studied by special scanners that detect radioactivity.

Leukocytes: White blood cells.

Lumbar Puncture: A diagnostic procedure that involves inserting a needle into the spine and taking a sample of spinal fluid for examination. Also called spinal tap.

Lymph: A nearly colorless fluid that bathes body cells and moves through the lymphatic vessels of the body.

Lymph Nodes: Bean-shaped structures scattered along vessels of the lymphatic system. The nodes act as filters, collecting bacteria or cancer cells that may travel through the lymphatic system.

Lymphangiography: An X-ray procedure that uses a radiopaque dye to examine the lymph system.

Lymphatic System: Circulatory network of vessels carrying lymph, and the lymphoid organs such as the lymph nodes, spleen, and thymus, that produce and store infection-fighting cells.

Lymphoma: A tumor of the lymphatic system.

Malignant: Tending to become progressively worse; in the case of cancer, it implies ability to invade, spread, and actively destroy normal tissue.

Metastases: Cancer growths that started from cancer cells shed by a primary cancer arising in another part of the body.

Monocytes: One type of white blood cell that destroys invading bacteria.

MRI *(magnetic resonance imaging):* A technique that uses magnetic fields and radio waves linked to a computer to create pictures of areas inside the body.

Neutrophils: A type of white blood cell that plays a major role in the body's defense against bacteria, viruses, and fungi.

Oncologist: A physician who specializes in cancer.

Oncology: Study of the physical, chemical, and biological properties and features of cancer.

Ostomy: A suffix that refers to a surgically created passage connecting an internal organ with the skin or other internal organs.

Pathologist: A physician who interprets and diagnoses the changes caused by disease in body tissue.

Petechiae: Tiny localized hemorrhages from the small blood vessels just beneath the surface of the skin.

Plasma: The liquid portion of the blood that contains numerous proteins and minerals and is necessary for normal body functioning.

Platelet: One of the main components of the blood that forms clots that seal up injured areas and prevent hemorrhage.

Port: Well-defined area mapped out for radiation.

Prognosis: An estimate of the outcome of a disease; a prediction.

Prosthesis: An artificial limb.

Rad: A unit of measurement for radiation.

Radiation Therapist *(radiation oncologist):* A physician who has had additional specialized training in using radiation to treat human disease. This specialist differs from the radiologist, whose primary role is one of diagnostician.

Radiation Therapy: Treatment using high energy radiation from X-ray machines, cobalt, radium, or other sources.

Radiation Therapy Technologist: A specially trained technician who assists the radiation therapist in giving external radiation treatments.

Radioisotope Studies *(scans):* A diagnostic procedure in which a harmless amount of radioactive chemical is injected into the bloodstream and concentrates in cancer cells. A scanning device passed over the body senses any radioactivity and makes a picture of its location in the body.

Radiologist: A physician with special training in reading diagnostic X-rays.

Red Blood Cells: Cells that carry oxygen to all the various organs and tissues of the body.

Recurrence: The reappearance of a disease after a period when symptoms had lessened or ceased.

Remission: The decrease or disappearance of cancer symptoms. Also the period during which this occurs.

Research Protocol: A general treatment plan that several hospitals use for one type of cancer.

Sarcoma: A cancer of connective tissue such as bone, cartilage, fat, muscle, nerve sheath, or blood vessels.

Toxicity: The quality of substances that causes ill effects.

TPN *(total parenteral nutrition):* The procedure in which nutrients are supplied directly to the bloodstream.

Ultrasound Studies: A diagnostic technique in which "pictures" are made by bouncing sound waves off organs and other internal structures. Tumors are identified from these pictures.

X-rays: High-energy radiation used in high doses to treat cancer or in low doses to diagnose the disease.

Notes

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